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ABSTRACT

This annual report on the quality of care for the mentally retarded in New York is organized in three sections focusing on obligations, opportunities, and the future, respectively. Subsections are organized into discussion, findings, and conclusions/corrective actions or recommendations. The first section examines issues in protecting individuals at risk in adult homes, in psychiatric centers, in emergency rooms, in correctional facilities, from abuse, from sexual abuse/exploitation, from child abuse, and from financial exploitation. The next section focuses on advocacy functions in specific situations and through the protection and advocacy networks. Specifically covered are closure of developmental centers, fiscal reforms, preventing deaths and promoting quality of life, responding, caring, and helping, legal advocacy, the surrogate decision-making committee program, and education and outreach. The section on "Looking Ahead" notes plans for a Children's Services Review, the Children's Medication Study, a study of discharge practices in psychiatric units of general hospitals, a review of familial abuse allegations of adults with developmental disabilities, a study on developmentally disabled parents, and a review of adult home deaths. Appendices show locations of programs and offices. (DB)

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NEW YORK STATE COMMISSION ON

QUALITY OF CARE for the Mentally Disabled

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ANNUAL REPORT 1990-91

QUANTITY	DESCRIPTION OF SERVICES--July 1, 1990 to June 30, 1991	Amount
25,461	Persons Served Through PADD, CAP, & PAMII Networks	
11,620	Complaints Acted Upon	
1,877	Recommendations Made	
868	Site Visits	
534	Deaths Investigated	
447	Surrogate Decision-Making Cases Reviewed	
199	Reports of Suspected Child Abuse Responded To	
288	Reports/Month of Suspected Adult Abuse	
6	Published Reports	
	TOTAL EXPENDITURES FOR SERVICES	
	State Purposes	
	Personal Services	$3,526,152
	Non-Personal Services	965,614
	Federal	
	Personal Services	724,180
	Non-Personal Services	1,843,183
	Other	49,537
	TOTAL	$7,108,666
	Discount %	
	NET	$7,108,666

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Title

1990-91
Date

Commission on Quality of Care for the Mentally Disabled
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FOREWORD

The past year has been one of uncertainty, change, and challenges. Between the budget deficit, fiscal cuts, large scale staff reductions and "bumping" of staff, rumors of plans to close some facilities and programs, and real plans with timetables to close others, this was a year of struggle and endurance for the mental hygiene system as a whole—its managers, work force, and, most importantly, those who needed the services and their families. It was a year of anxiety and pain which comes with the uncertainty and changes driven by factors beyond one's control.

In this environment, the attention of program managers and staff was sometimes understandably diverted from the needs of the people they serve to more immediate concerns about continued funding and job security. The "testing" that all programs and staff underwent during this year prompted us to consider again the difficult circumstances under which so much of the system operates, and to appreciate with fresh eyes the successes that are achieved. Despite these difficulties, the Commission generally found agencies and staff responsive to our suggestions, recommendations and offers of training and technical assistance.

The Commission itself was not immune to the same forces affecting the rest of state government, but despite the major change in the structure of the Commission, replacing full-time commissioners with volunteer members, along with other cutbacks in funding, we have made a concerted effort to preserve our high level of expectations in fulfilling our obligations, while, at the same time, searching for opportunities in the midst of the fiscal crisis, opportunities for change which would yield the most for the people we as a Commission, and the system as a whole, are intended to serve.

The economic difficulties being experienced, and the sometimes desperate search for funds to preserve essential services, rekindled our sense of outrage at the fiscal abuses we witness where funds intended for care and treatment have been diverted to personal profiteering and gain, and where people in need have been abused, exploited, or neglected. We—all of us—must do better to carry out the basic governmental obligation to protect the interests of those who depend on us.

As this year's report summarizes, the Commission has endeavored to fulfill its statutory obligations of oversight and protection of people at risk in various settings in institutions and the community. We have also tried to find, support, and reinforce opportunities for change.

New York has come to realize that our historic overreliance on expensive institutional services has been not only cost-*in*effective, but also inappropriate. Perhaps nowhere are opportunities more abundant than in reducing reliance on unnecessary and expensive institutional services, and reinvesting funds in community services that offer choice, meaningful rehabilitation, and the chance to become part of a community. In managing our money, we have the opportunity and obligation as a state to be more vigorous in our reforms to eliminate both profit-making abuses and wasteful practices in the system of care.

With the preparation of this annual report we acknowledge the support of the Governor and the Legislature and their respective staffs. We also acknowledge the cooperation of facilities and programs we oversee. Finally we acknowledge the assistance—as well as the just anger and the courage—of consumers and families in enabling us to see the human consequences of policies and practices. Each of these contributions help create a climate which fuels the untiring efforts of an exceptional group of women and men who staff the Commission.

Clarence J. Sundram

Clarence J. Sundram
Chairman

Elizabeth W. Stack

Elizabeth W. Stack
Commissioner

William Benjamin

William P. Benjamin
Commissioner

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The Commission continues to exercise its protective and advocacy obligations through monitoring and investigative activities in a variety of settings, as the following pages illustrate.

OBLIGATIONS: PROTECTING INDIVIDUALS AT RISK

A fundamental duty entrusted to government by those who are governed is protecting its citizens from harm, particularly those citizens, who, for various reasons, are dependent and vulnerable. This role has been described as "parental" (*parens patriae*); what parents worthy of the name would want to stand back and allow their children to be harmed?

In the past year, the Commission, as an independent New York State agency, continued to exercise its protective and advocacy obligations through monitoring and investigative activities in a variety of settings, including adult homes, psychiatric centers, emergency rooms, children and adult residential settings, as the following pages illustrate.

IN ADULT HOMES

The Commission's report, ***In the Matter of the Jacob Home***, details the failure of several agencies to effectively discharge their obligations and protect the well-being of mentally ill men who lived, and died, in intolerable conditions in an illegally-operated adult home.

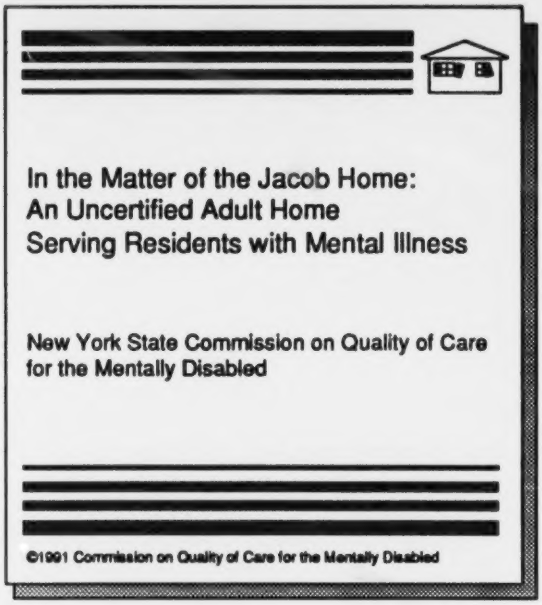
The Commission's investigation into the matter of the Jacob (a pseudonym) home was prompted by the deaths of two outpatients of the Sunrise Psychiatric Clinic. The men died in the Jacob home days apart in late 1989; one of tuberculosis and the second of pneumonia a day after being released from a hospital where he had been treated for hypothermia after having been found unconscious on the floor of the home. According to the Medical Examiner, both men appeared to be undernourished.

An unannounced visit to the home by Commission staff found seven other men living in the house. Most had been discharged to the residence from state psychiatric hospitals and all were receiving outpatient case management services from the Sunrise Psychiatric Clinic. Most were poorly dressed, unshaven and dirty; throughout, the house smelled of urine and feces, and was filthy. One resident was found confined to bed, covered with feces and when the operator's son was given an opportunity by the Commission investigator to tend to the man, he declined saying, "That's all right, he's always like that." In addition to advocating for the placement of these men in appropriate residences, the Commission sought to determine how they came, and were permitted, to live under such conditions.

FINDINGS

☐ The State Department of Social Services (DSS) knew as early as 1984 that Ms. Jacob was illegally operating the residence as an uncertified adult home but failed to take effective action. Instead, DSS tolerated repeated delays in, and evasions of, regulatory action, ultimately aborting all efforts at enforcement until six years later when the mental health agency serving the home's residents facilitated their transfer to licensed facilities at the Commission's urging.

☐ In violation of discharge planning requirements contained in Section 29.15 of the Mental Hygiene Law, between 1983 and 1987, Kings Park and Central Islip Psychiatric Centers inappropriately released patients requiring an adult home level of care to the Jacob residence—although it was not certified as an adult home—apparently with little follow-up to monitor their well-being and to determine whether the residence was appropriate to their needs.



In the Matter of the Jacob Home:
An Uncertified Adult Home
Serving Residents with Mental Illness

New York State Commission on Quality of Care
for the Mentally Disabled

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☐ The Sunrise Psychiatric Clinic, which was responsible for providing case management services to the home's residents to monitor and address their needs, neglected to maintain regular contact with the clients, to assess their service needs, and to resolve complaints expressed by the residents about the home or their treatment, and problems which were clearly obvious.

☐ Consequently, mentally ill men were placed and left to reside under conditions, which if found in a natural family setting would likely result in the parents being charged with child abuse or neglect and the children being removed from the home. The residents slept on mattresses on floors in unsanitary conditions and unsafe environs; during one period when the home lacked heat, the oven was used for warmth and two residents were hospitalized for hypothermia, one of whom died following his return to the home. The men complained of not being fed properly and were malnourished. Some asked for transfer to other homes or placement in social or recreational programs; their requests fell on deaf ears. The residents' medical needs were neglected as the operator failed to take them to medical appointments and case managers failed to monitor services reportedly to be given by other providers. This neglect resulted in the death of one resident, who died of tuberculosis months after the operator failed to bring him back to a physician's office to determine whether the results of a skin test for the disease were positive.

Conclusions/Corrective Actions

The Commission concluded that the tragedy of the Jacob home situation was not just that mentally disabled individuals long suffered intolerable conditions, but that they suffered because social service and mental health agencies, in responding to the needs of dependent persons who had no one willing or able to care for them, breached their public duty to act with the same interest, compassion and commitment as a parent would toward a child.

In view of the various laws, regulations, policies and professional standards which already exist to empower and guide human service agencies in their mission regarding vulnerable people, the Commission saw no need to formulate recommendations which would address the breach of duty demonstrated in this case. Rather, the Commission called upon the involved agencies to critically examine their conduct in this matter, to determine why such a tragedy was allowed to unfold since 1984 and to reaffirm, through corrective action, the trust vested in them by the citizenry to protect its most fragile members.

Following release of the Jacob Home report, the Department of Social Services promised to revamp its enforcement practices relative to unlicensed adult homes and to secure their swift closure through court action, if necessary.

The Office of Mental Health also initiated corrective measures. In addition to re-articulating facilities' obligations under discharge planning laws, the Office is formulating practice standards, or expectations, to guide the delivery of case management services and to empower case managers to serve as true advocates for mentally disabled persons by focusing on their needs.

The Sunrise Psychiatric Clinic took corrective actions including counseling key staff, modifying the manner in which case management services are reviewed and supervised, and developing training programs for case managers.

Newsday August 29, 1991

Criticism in Patient Deaths

Panel says mental health officials overlooked 'squalid' conditions

By Jim Puzzanghera
STAFF WRITER

A mental health watchdog commission yesterday blasted two state agencies and a private psychiatric clinic for the 1989 deaths of two mentally ill men who were living in an illegal Wyandanch community residence the commission described as having "deplorable" and "squalid" conditions.

In a report released yesterday, the New York State Commission on Quality of Care for the Mentally Disabled charged that the state Department of Social Services and Office of Mental Health were aware of the unlicensed residence for years and failed to shut it down or withdraw the residents from the house even though they received inadequate care there.

"Everybody right across the board dropped the ball on this one," said Gary Masline, a spokesman for the commission. Citing mental health confidentiality laws, the commission did not release the names of the two men who died at the home.

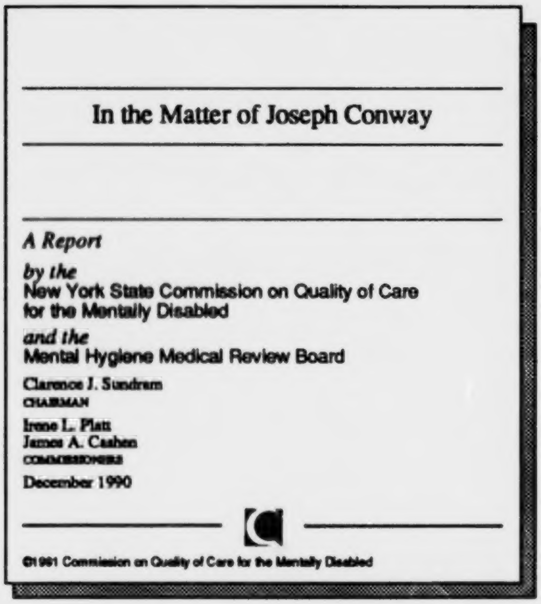
A middle-aged man died on Nov. 28, 1989, of pneumonia after being released from the hospital, where he was treated for hypothermia because the house lacked heat, the report said. And a 55-year-old man was found dead there three days later of tuberculosis after operators of the home failed to follow up on a tuberculosis test, the report said.

The commission also would not release the name of the woman who ran the illegal adult home, first from a house on Lake Place in Wyandanch, then from a house on 31st Street. The commission said it found that the seven residents of the illegal adult home on 31st Street slept on mattresses on the floor in "filthy and unsafe conditions," and were "malnourished, filthy and poorly dressed, and lived in an environment smelling of excrement."

Robert Spoor, a spokesman for the state Office of Mental Health, admitted workers at the Kings Park and Central Islip Psychiatric Centers made mistakes in not checking to confirm that the home to which they released patients was licensed. However, officials with the Department of Social Services said they found more mistakes with the commission's report..

"The report is replete with errors of fact and it conveys a basic misconception about the DSS and its regulation of adult homes," said Terrance McGrath, a social services spokesman.

The report charged that social services officials first learned of the illegal home in the middle of 1983 and dragged their feet in taking enforcement action over the next six years. It also charged that workers from the two psychiatric centers did little follow-up to determine the care being provided there, and that the Sunrise Psychiatric Clinic in Amityville, where the men were receiving outpatient treatment, did not properly monitor the services. . . .



In the Matter of Joseph Conway

A Report
by the
New York State Commission on Quality of Care
for the Mentally Disabled
and the
Mental Hygiene Medical Review Board
Clarence J. Sundram
CHAIRMAN
Irene L. Platt
James A. Cashen
COMMISSIONERS
December 1990

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The Commission investigation and report, *In the Matter of Joseph Conway,* is another illustration of the difficult challenges present in caring for people diagnosed mentally ill residing in adult homes, and the need to ensure that the Department of Social Services and the Office of Mental Health offer care providers sufficient guidance and oversight in the delivery of coordinated services for this population.

FINDINGS

- ☐ Mr. Conway (a pseudonym) was a bright, articulate 43-year-old mentally ill resident of an adult home who exposed deficiencies and advocated for resident rights, but who also harassed residents and provoked staff. He committed suicide following release from jail after having been arrested as a result of incidents at the home.
- ☐ Responsible agencies failed to meet the challenges presented by Mr. Conway. Staff of his adult home evidenced little understanding of, or skill in dealing with, his behaviors and resorted to physical abuse or mistreatment in attempting to manage his behaviors in the home. Despite warning signs of an escalating crisis in the residence, and allegations and evidence of the facility's inability to appropriately manage Mr. Conway's behaviors, staff of mental health agencies and the Department of Social Services failed to intervene.
- ☐ That responsible agencies failed to take appropriate actions was due, in part, to systemic problems, including poor sharing of information and the absence of policies to guide crisis intervention services. To an equal extent, however, the inaction was due to a *laissez-faire* attitude on the part of key agencies, which resulted in the staff of the home having to fend for themselves in managing a crisis situation.
- ☐ Absent clinical or administrative interventions, involvement by the criminal justice system was deemed the only available remedy to the crisis, and was employed. The trauma of incarceration may have contributed to Mr. Conway's suicide.

RECOMMENDATIONS

The Department of Social Services and the Office of Mental Health were urged to:

- ☐ provide training to the adult home staff to sensitize them to the needs of mentally ill persons and appropriate means for responding; evaluate whether other residences serving large numbers of mentally ill persons also need such training;
- ☐ improve incident reporting and complaint investigation standards and regulations to ensure timely and comprehensive follow up, including remedial and corrective action;
- ☐ enhance information sharing among agencies regarding reports of abuse or neglect of residents; and
- ☐ create a mechanism to trigger special interagency clinical and administrative reviews and intervention when crises arise in adult homes.

RESPONSES

In response to the investigation and report, the Department of Social Services promised to work closely with the operator and staff of the residence to ensure the protection of all residents. DSS promised to review the corrective action plan submitted by the operator. DSS and OMH convened an interagency workgroup to address issues including but not limited to: admission criteria to adult homes for individuals with mental illness; crisis intervention for adult home residents in need of such services; sharing information among service providers involved in the lives of adult home residents, particularly with regard to allegations of abuse and neglect; and establishing a process whereby DSS and OMH could jointly inspect and review the operations of adult homes serving a significant number of mentally ill individuals.

In October 1991, the interagency workgroup developed a preliminary and confidential report offering action plans to address these issues. The preliminary report has not yet been finalized.

As this annual report goes to press, the Commission initiated an investigation into the September 1991 suicide of another resident of the home where Mr. Conway lived.

Adult Homes Follow-Up

Since the release of the Commission's report, *Adult Homes Serving Residents with Mental Illness: A Study of Conditions, Services, and Regulation* in October 1990, Commission staff have continued to receive serious complaints about the quality of care and treatment provided for residents of these homes. These complaints referenced environmental problems such as roach infestation and filthy living conditions, maintenance issues such as no heat in the winter and no hot water, inappropriate disburse-

A Sample of Adult Home Complaints

☐ In the middle of the winter a resident of an adult home complained there was no heat in the bedrooms. The complainant also alleged the home's staff were stealing the residents' personal belongings.

☐ A resident of an adult home reported that a man who had been loitering around the home had entered the home during the night and raped an elderly female resident.

☐ A CSS caseworker contacted the Commission and reported that residents of an adult home are not provided with assistance in completing their personal hygiene and that most recently, an elderly resident came to a hospital emergency room for medical care wearing urine-soaked clothing. During the Commission's follow-up with the hospital, the physician also complained there was not a clean area on this individual's body and that it appeared as if he had not bathed in weeks.

☐ A legal aid advocate reported the administrator of an adult home was inappropriately disbursing the residents' personal allowances and owed some of the residents between $100 and $1,000.

☐ An advocacy program reported that a resident of an adult home, who was abusing crack, had obtained a pass key to all the residents' bedrooms and was stealing their personal belongings (e.g., radios, televisions, stereos) and selling them to purchase drugs. The complainant also noted that, with the exception of attempting to evict this individual, the home was not implementing any actions to address the issue (e.g., additional security measures).

☐ A resident of an adult home complained the home was infested with roaches, the bedrooms were dirty, and the floors throughout the facility were filthy and stained.

☐ A resident of an adult home wrote a letter to the Commission reporting that the water pipes in the ceiling of her bathroom were leaking. The complainant also reported that, in response to reporting this to the home's administrator, she was being threatened with eviction.

☐ Staff from a local mental health program reported the water in an adult home in their community was repeatedly turned off for two or more hours a day due to problems with the home's septic system. During these periods, which last up to seven days, there were no provisions for the residents to toilet. The complainant also reported the home is not clean and the staff are verbally abusive to the residents.

☐ A resident advocate reported that the administrator of an adult home argued with a resident for smoking in the dining area and that during the altercation the administrator allegedly pushed the resident to the ground, repeatedly kicking him in the stomach.

☐ Staff of the on-site CSS team reported that during the previous evening a 55-year-old female resident of the adult home was found in her bedroom bleeding profusely from the vagina complaining that a staff person from the home had raped her.

ment of resident funds, and crimes committed on-site. As shown in the figure on the previous page, the concerns of the complainants have been wide-ranging, but many of the complaints have centered on very serious matters.

In total, the Commission has received over 100 complaints from adult home residents, their families, and advocates during the year. Since the Commission's jurisdictional access to adult homes (except in the cases of resident deaths) closed with the completion of its legislatively-mandated study, in most cases the agency's role has been to try to broker help from the Department of Social Services, the Office of Mental Health, or other advocates and agencies with access to investigate and assist the complainant.

Whenever the complainant was willing, these complaints were referred to the Department of Social Services which has primary responsibility for the oversight of adult homes in New York. Additionally, for some of the more serious concerns, regional Protection and Advocacy Agencies for Mentally Ill individuals have been able to intercede with legal assistance on behalf of the complainants. In some cases, the Ombudsman Program with the State Office of the Aging and staff from Regional Offices of the Office of Mental Health have also been helpful.

Overall, however, the Commission's experience in "brokering" these complaints has reinforced that there is limited individual advocacy and support available to residents of adult homes who believe that their rights are being violated or that they are being poorly or unfairly treated. The Commission continues to experience the lack of timeliness and comprehensiveness of the Department of Social Services' investigations. In a number of instances, the DSS has investigated complaints by talking only with the home administrator, neglecting to interview the complainant or other residents. Too often, on-site mental health staff do not perceive their role to advocate for and assist the residents in dealing with adult home operators and staff.

These observations have led the Commission to advocate strongly with the Governor's Office and the Legislature for systemic reforms in the manner in which the state regulates adult homes, including ensuring a more effective grievance and complaint investigation capability within government to respond to adult home residents.

ADULT HOMES LEGAL ADVOCACY

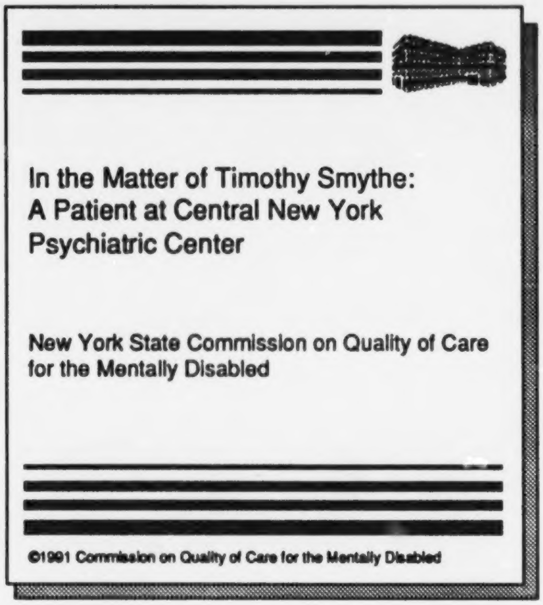
Disability Advocates, Inc. a Protection and Advocacy Office for Persons with Mental Illness in Albany, received a $75,000 one year grant award from the New York State Interest on Lawyer Accounts (IOLA) to undertake regional and statewide advocacy on behalf of mentally ill adult home residents. These efforts will include: site visits to interview residents and assess conditions; assistance to resident councils and long term care ombudsmen; cooperative efforts with residents' attorneys and legal services organizations; work with the Department of Social Services and the Office of Mental Health to enhance regulation enforcement efforts; appropriate legislative and administrative advocacy; and litigation. All these efforts are to ensure that the focus on problems in adult homes continues to receive scrutiny and that significant improvements are made in the way these homes serve mentally ill residents.

As this report goes to print, two of the Protection and Advocacy offices have initiated litigation against adult homes with seriously deficient conditions, seeking damages on behalf of the residents.

IN PSYCHIATRIC CENTERS

Inadequate supervision by direct care staff, and the failure to report and investigate incidents and take corrective measures in a timely manner, permitted two patients at Central New York Psychiatric Center to run an extortion ring, using physical and sexual assaults and threats to gain compliance from fellow patients. The Commission report, *In the Matter of Timothy Smythe: A Patient at Central New York Psychiatric Center*, points out the breakdown in the facility's handling of the incidents which jeopardized patient safety.

According to the report, patient Timothy Smythe (pseudonym) openly ran a "store" on the ward, selling candy, cigarettes, and snacks obtained from the PX at Griffis Air Force base in nearby Rome and supplied to him by visiting friends. He also reportedly extorted money, food, and cigarettes from weaker patients, with another patient providing the "muscle," victimizing uncooperative patients through beatings and sexual assaults.



In the Matter of Timothy Smythe:
A Patient at Central New York
Psychiatric Center

New York State Commission on Quality of Care
for the Mentally Disabled

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FINDINGS

☐ Although discovered in August 1989 when one of the two ringleaders wrote a letter confessing some of his activities, the final written investigation report was not delivered to the director until February 1990, six months later. The director took no action until May 23 when he forwarded it to the facility's Incident Review Committee.

☐ Direct care staff were aware of the store's exploitation of patients and assaults, and failed to report and investigate the incidents. Facility staff's failures to report hindered the protection of patients from harm including exploitation and, in its most serious form, assaults and rape. This violated state regulations and inhibited established investigation and reform processes.

☐ This lack of action shielded these events from extensive investigation, prevented the incidents from receiving the level of administrative scrutiny they warranted, thwarted effective remediation and kept the information from external parties such as the Commission, Mental Hygiene Legal Services and the Board of Visitors, all of which should have received notice of such events.

ACTIONS

☐ Once they received the report, the facility's Incident Review Committee acted expeditiously and made additional recommendations, many centering around issues of lax supervision and problems in patient care and treatment.

☐ In response to their own and Commission findings, the facility undertook a number of corrective measures, including major revisions in the

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Utica Observer-Dispatch, Wednesday, Aug. 21, 1991

EDITORIAL

Questions in need of answers

The Central New York Psychiatric Center in Marcy, which houses mentally ill prisoners, must be one of the most difficult places to work in New York State. Few of us would want to spend our days with disturbed people who often are prone to violence.

So some compassion must be extended to employees who apparently allowed an extortion ring to operate undisturbed at the center over a period of several months. Still, the report on the incident by the state's Commission on Quality of Care for the Mentally Disabled is a cause for serious concern.

"There was a sense," says commission chairman Clarence Sundram, that "the patients had the run of the place and the staff was a little leery of tangling with them."

The center's director, Hal Smith, has acknowledged that his staff didn't act fast enough in dealing with the ring and said it wouldn't happen again.

Earlier this summer the state Commission of Correction faulted psychiatric center aides in the deaths of two inmates, saying too much force had been used to restrain them. One of those cases went to a grand jury, which found no basis for criminal charges.

It could be argued that in one case the aides are accused of doing too much, and in another of doing too little. Perhaps. No outsider can say with certainty that anything is seriously wrong. But enough troubling questions have been raised to call for more detailed answers. The public deserves assurances that this difficult psychiatric center is being properly managed.

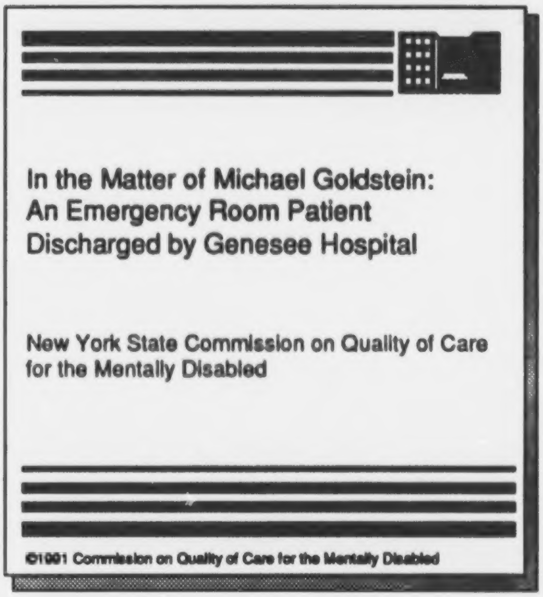
incident reporting and review policies and processes, and in procedures for insuring enhanced supervision of patients monitored by administrative rounds.

- ☐ Since the Commission report was issued, the facility has taken a number of additional steps to improve both security at the facility and its reporting procedures. For example, a new Chief of Security has been appointed, and one security supervisor has been removed from mainly administrative responsibilities and placed as a line supervisor.
- ☐ Ongoing review of incidents have revealed that a significant number of incidents occurred in bathrooms. This finding has stimulated the facility to make a number of modifications to the physical layout of the bathrooms to increase patient safety while maintaining privacy.
- ☐ The facility states that the revised incident reporting procedures have significantly improved the process for reporting and documentation of incidents, as well as the review, notification, and investigation functions. As one measure of that improvement, the facility notes that the total number of incidents reported has increased 11% from the first half of 1990 to the first half of 1991.
- ☐ To ensure that these improvements continue, OMH has agreed to review the entire incident review protocol at Central New York Psychiatric Center during the first quarter of 1992. These findings are to be shared with the Commission.

IN EMERGENCY ROOMS

The Commission recognizes that the evaluation of patients with symptoms of mental illness presenting at emergency rooms and the determination of the need for involuntary inpatient psychiatric treatment is an enterprise fraught with risks. While history makes clear, and mental health professionals acknowledge, that it is impossible to predict accurately the likelihood of violence toward self or others presented by any specific patient at any particular time, such lack of certainty should not preclude psychiatrists and other mental health professionals from taking reasonable steps to minimize the risks.

The Commission report, *In the Matter of Michael Goldstein: An Emergency Room Patient Discharged by Genesee Hospital,* details several cases where tragedies ensued when prospective patients were released from emergency rooms following a decision not to admit them. The subject of this report, Mr. Goldstein (a pseudonym) told an emergency room physician performing a physical for purposes of medical clearance that he was hearing voices telling him to kill himself and other people. He was given medication and held for several hours, evaluated by two licensed social workers consulting by phone with a psychiatrist, then released with a dose of medication to take at home and a prescription. Within hours of his release from the emergency room, he allegedly killed two men.



In the Matter of Michael Goldstein:
An Emergency Room Patient
Discharged by Genesee Hospital

New York State Commission on Quality of Care
for the Mentally Disabled

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The Commission found that:

- ☐ The psychiatrist who made the decisions regarding medication and discharge never personally examined Mr. Goldstein but based his determination on information provided by the Psychiatric Assessment Officers (licensed social workers) and the ER physician.
- ☐ Mr. Goldstein's command hallucinations to kill himself and others were not adequately evaluated and were not reported to the psychiatrist who prescribed medication and ordered his discharge.
- ☐ The hospital emergency room documentation did not include information on the command hallucinations.

☐ The hospital's policies gave no guidance on the circumstances under which a psychiatrist should personally examine a patient as part of the emergency room evaluation, and lacked procedures for evaluating potentially violent patients.

CONCLUSION, RECOMMENDATIONS, RESPONSE

Although no one can ever state with certainty that the calamitous events would have been averted by a different evaluation process, the Commission believes that corrective measures are warranted to provide additional protections to patients and the community. To this end the Commission report recommended:

☐ OMH should require emergency room policies describing patient profiles and circumstances needing personal examination by experienced psychiatrists prior to discharge, especially for patients who may harm themselves or others;

☐ Hospitals should consider establishing a holding/observation bed for 24-hour mental status observation before admission or discharge, especially when a psychiatrist is not always available on site;

☐ Genesee Hospital should revise its emergency room forms to include critical information from mental status examinations, such as whether or not homicidal/suicidal command hallucinations are present.

In response to this report, the Office of Mental Health agreed on the need to establish standards of practice for mental health professionals in emergency rooms when making such discharge decisions and agreed to take the lead in initiating discussions in psychiatric circles about the specific criteria to be used.

Senior level clinical policy makers at OMH, including Chief Medical Officer Dr. John Oldham met with relevant professional groups such as the Emergency Psychiatry Committee of the New York County District of the American Psychiatry Association, Emergency Psychiatry Committee of the Area II Division of the APA, the members of the rural Comprehensive Psychiatric Emergency Program to seek their involvement, guidance and assistance in establishing a professional standard in this question. Bringing into existence and implementing this standard of professional practice will require that these efforts be on-going. The Commission will continue to encourage OMH to sustain the effort.

OMH and the Department of Health (DOH) have been meeting to establish collaborative efforts for improving psychiatric treatment in general hospital emergency rooms. DOH has the regulatory and enforcement authority over emergency rooms and both OMH and DOH are planning how to best utilize this DOH regulatory authority to implement improved safeguards for identifying patients at risk and securing appropriate evaluation and treatment. OMH will function in a guidance role, using its background and expertise in the area of psychiatric services.

Rochester Democrat and Chronicle June 15, 1991

Genesee Hospital staff failed to report suspect's delusions

By Vincent Taylor
Democrat and Chronicle

The emergency room staff at Genesee Hospital failed to adequately evaluate the mental state of a Rochester man who is accused of stabbing two people to death hours after he was released from the hospital in October, a state commission reported yesterday.

The emergency room staff failed to report to the psychiatrist on call that the man believed he was being commanded to kill himself and others, according to the report by the New York State Commission on Quality of Care for the Mentally Disabled. The psychiatrist prescribed tranquilizers and ordered the man discharged without personally examining him, relying instead on telephone conversations he had with the psychiatric social workers and an emergency room physician who evaluated him, the mental health watchdog group found.

The patient, identified in the report by the pseudonym Michael Goldstein, is now in the Monroe County Jail. He is scheduled to appear in court on July 3.

The man's real name is Gary Rosenberg, according to a source familiar with the case. After he was arrested, Rosenberg was first held in the forensic unit at the Rochester Psychiatric Center before being sent to the Monroe County Jail.

Rosenberg, 34, pleaded innocent to two counts of second degree murder stemming from the Oct. 8 slaying of Dale Auld, 31, and Jose Luis Martinez, 34, who both lived at the Elk Hotel, 113 N. Clinton Ave. Rosenberg also lived there.

The commission said Genesee Hospital violated no state rules in its handling of patient. But because of the incident and others like it around the state, the commission is seeking new rules that detail when psychiatrists should personally examine emergency room patients before they are discharged. . . .

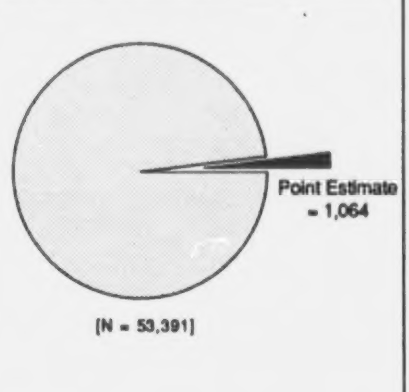
IN CORRECTIONAL FACILITIES

In 1988, the State Legislature requested the Commission to conduct a study to determine the number of inmates in the New York State local jails and prisons who were developmentally disabled. This request came in the wake of hearings held in the fall of 1987 by the State Senate Select Committee on the Disabled and the Assembly Standing Committee on Correction and Mental Health, Mental Retardation and Developmental Disabilities regarding concerns about criminal offenders who were developmentally disabled.

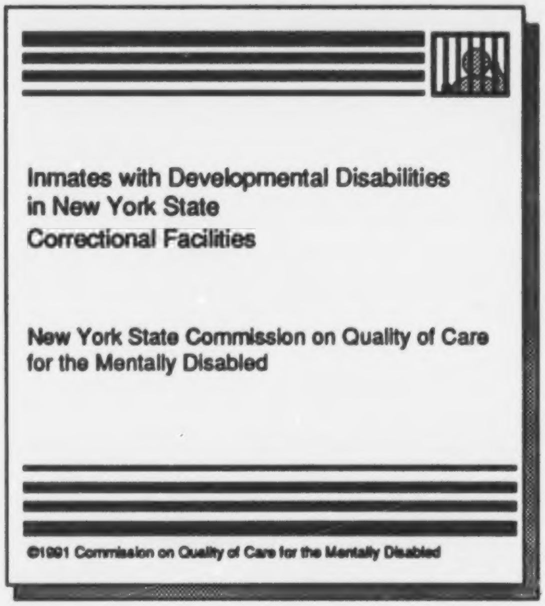
These hearings revealed common beliefs that individuals with developmental disabilities are at a disadvantage when dealing with the criminal justice system. These disadvantages may include unfair treatment by the judicial system and inadequate identification and programming within the correctional system.

After discussion with key legislative staff, it was agreed that the focus of the study would be on estimating the number of developmentally disabled offenders in the state prison system; and that the study of the local jails, although important, would be deferred because of the unavailability of resources. Even with the narrower focus, this study on developmentally disabled offenders was the largest of its kind. The Commission published the study as *Inmates with Developmental Disabilities in New York State Correctional Facilities* in March, 1991.

Estimated Number
of Developmentally Disabled Inmates
in New York State Prisons



Prevalence Rate of DD Inmates is 1 to 3%



Inmates with Developmental Disabilities
in New York State
Correctional Facilities

New York State Commission on Quality of Care
for the Mentally Disabled

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FINDINGS

- ☐ Contrary to many estimates, the study found that a relatively small proportion of prison inmates, only 1-3%, met the federal statutory definition of developmental disabilities.
- ☐ These inmates with developmental disabilities had longer prior histories of criminal convictions with more serious offenses than other state prison inmates. However, the developmentally disabled inmates were no more likely to have served a prior jail or prison sentence. This finding suggests that these inmates may have been treated more leniently in their past sentencing decisions.
- ☐ Although the academic achievement tests and the Revised Beta IQ tests administered to incoming inmates at reception were not reliable in identifying the small percentage of developmentally disabled inmates, the correctional officers at the Reception Centers had identified better than half of such inmates through observation and interaction and recommended them for further testing or placement in a special unit.
- ☐ The shortage of Spanish-speaking staff and the absence of tests in Spanish at reception resulted in unreliable test scores for many of the Hispanic inmates entering the correctional system. Test scores from English tests were lower than other measures of intelligence indicated.

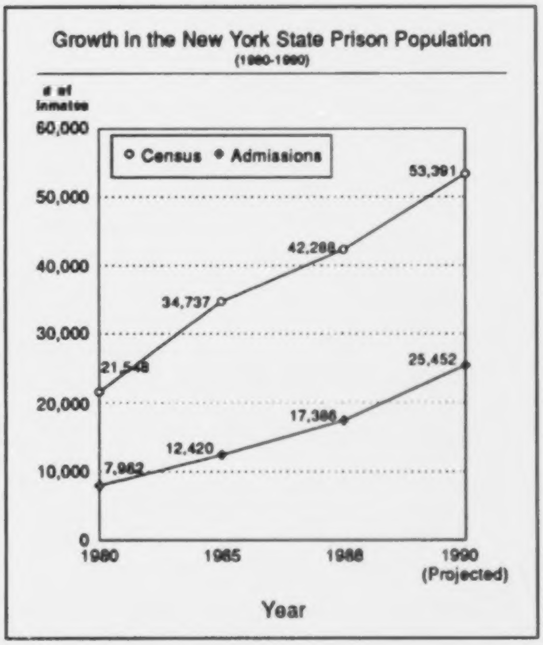
☐ The majority of inmates with developmental disabilities are "mainstreamed" into the general prison population. Although they may have more difficulty in adjusting to prison rules and routines, as documented by more "rule infractions" on their prison records, these inmates were no more at risk of serious injury or losing "good time" against their parole date than other inmates.

☐ For the minority of developmentally disabled inmates, (approximately 10 percent of all developmentally disabled inmates), placement was provided at two special units (Wende Special Needs Unit and Clinton's Assessment and Program Preparation Unit) designed to serve inmates with disabilities.

RECOMMENDATIONS

☐ Specialized training to correctional officers to assist in identifying developmentally disabled inmates utilizing materials already developed by the State Office of Mental Retardation and Developmental Disabilities for the criminal justice system.

☐ Recruit more Hispanic staff for Reception Centers and cease using English-only achievement and intelligence tests for Spanish-speaking inmates.



☐ Modestly expand the use of special units for the developmentally disabled inmates with some increase in the staffing and resources that would enhance living skills training and rehabilitation programs.

☐ Integrate life skills training for *all* prisoners with these limitations. 'Mainstreaming' developmentally disabled inmates with other inmates who also have specials needs in life skill areas to prepare them for community placement would minimize stigmatization and parole difficulties that often accompany inmates who are identified and segregated because of their disabilities.

RESPONSE

The Department of Correctional Services in its response stated the Commission study will "provide our department with a sound empirical basis for our program development efforts well into the next century. It will provide us direction in both the global planning efforts department wide as well as giving us direction at the programmatic and individual level as well."

In 1991, two more special units for developmentally disabled inmates began operation: a unit similar to Wende's was developed at Sullivan Correctional Facility and a program at Arthurkill Correctional Facility that provides services to both developmentally disabled and others in need of a transitional setting prior to parole.

FROM ABUSE

One fundamental method for institutions to fulfill their obligations to protect residents from harm is to protect them from abuse and neglect by staff. In order to do this well, facilities must have policies and procedures which guide the reporting, investigation and review of incidents and which identify corrective actions to prevent the recurrence of similar incidents. Regulations of both the Offices of Mental Health and of Mental Retardation and Developmental Disabilities require facilities to report allegations of abuse to the Commission. Also, the Child Abuse Prevention Act of 1985 authorizes the Commission to investigate allegations of abuse and neglect made to the State Central Register concerning children in state-operated or licensed residential mental hygiene facilities. The Commission's work in investigating allegations of both adult and child abuse has permitted us to redress grievances on behalf of individual residents by ensuring a fair and impartial investigation and review of an incident, and has enabled us to also effect systemic change, including the revision of policies, training of special investigators, the enhancement of Incident Review Committee deliberations and the establishment of systems for ensuring the effective implementation of corrective actions.

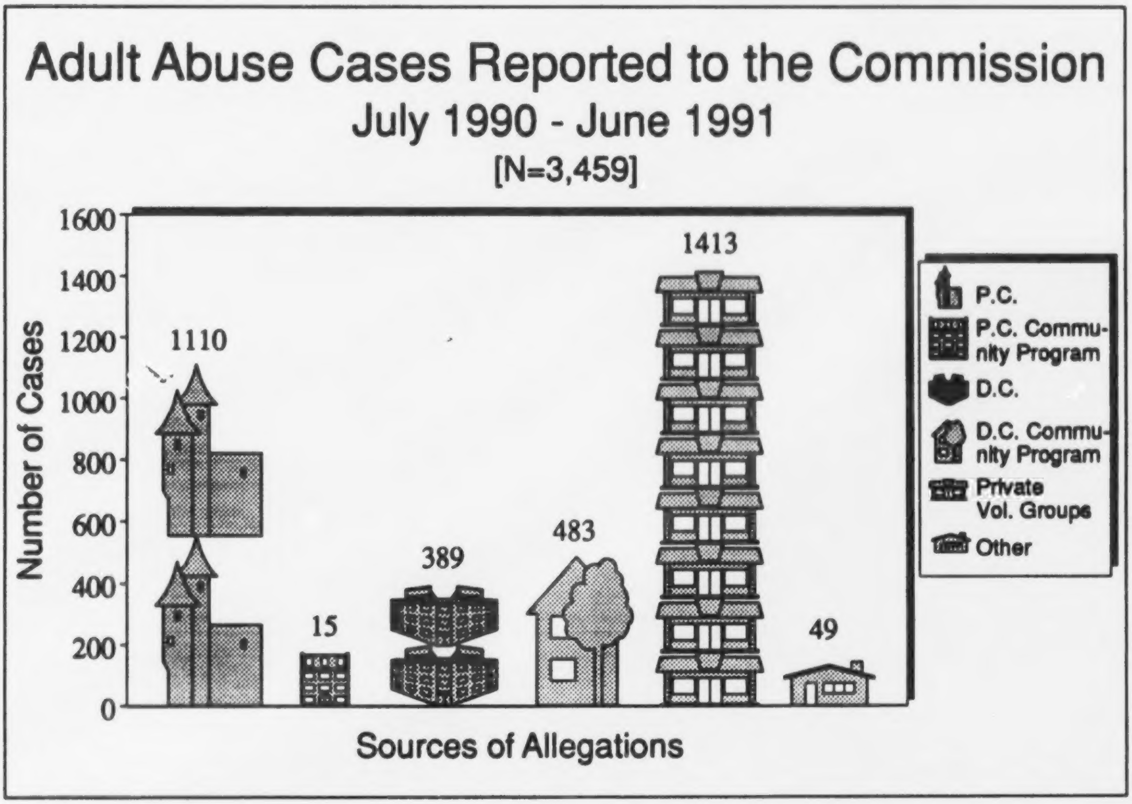
ADULT ABUSE

The cases cited below are representative of the allegations of adult abuse/neglect which Commission staff either investigated or critiqued the facility's complete investigation.

- ☐ The Commission received multiple allegations from an upstate DDSO of abuse of residents by an employee at one of its residences, including allegations of neglect and sexual abuse. The employee resigned prior to interrogation.

  The Commission reviewed the DDSO's investigation and found that the incidents had not been properly reported, investigations into these incidents were inadequate, and the Special Review Committee had failed to make needed recommendations. For example, staff had heard the employee make inappropriate remarks to four clients, suspected he had sexually abused two clients, were aware that he inappropriately bathed a female resident with the bathroom door closed and improperly left a physically disabled resident alone in a standing position. Yet, staff failed to make their concerns known in a timely fashion. Further, a nurse and physician's assistant failed to report that during a medical exam, they found that the female resident who had been bathed by the employee was subsequently found to have shaven pubic hair.

  The DDSO's investigation included interviews with staff, but the content of some of these interviews was not recorded, nor were written statements taken; their report did not include the findings of the medical exam or describe any attempts to determine who did the shaving, when and under what circumstances. It also failed to verify the accuracy of a staff member's observation that another male resident had increased his self-stimulation since the employee's


Adult Abuse Cases Reported to the Commission
July 1990 - June 1991
[N=3,459]

assignment to the home, and did not address allegations involving inappropriate sexual remarks to a third resident.

The Incident Review Committee did not address the investigator's recommendation to provide incident report training, nor did it identify any of the shortcomings of the investigation.

The Commission identified the deficiencies and recommended that the Quality Assurance department review the incident reporting, investigation, and review process and take corrective action to ensure the allegations of abuse are investigated and reviewed properly, train staff in incident reporting and issues surrounding intimate care and personal privacy.

In response, the DDSO employed a combination of counseling, progressive discipline and training to address deficiencies in incident reporting, initiated written staffing assignments, and created a committee on intimate care. Further, they developed plans to conduct an internal audit of closed IRC cases, train staff based upon the findings, and train Incident Review Committee members on the development of recommendations. The Commission will continue to monitor the implementation of corrective actions.

❑ The Commission's Quality Assurance Bureau was requested by the director of a facility to assist in investigating allegations of sexual abuse of a patient by a staff member, and the counter allegation by the target employee that he was being harassed by fellow employees and that the sexual abuse allegations were a setup.

We found no evidence to support the sexual abuse allegation. However, Commission work revealed that many signals of the seriousness of the animosity between employees had been left unheeded, resulting in a situation that was as difficult to unravel as a ball of tangled yarn. The facility reassigned two key administrators, and made significant changes in its procedures for responding to abuse allegations.

❑ In reviewing an allegation that two adolescents had engaged in sexual activity while on the mental health unit of a medical center, the Commission determined that the facility investigation of the circumstances was seriously deficient, in part, because this large and well-known facility had no trained investigators and had assigned portions of the investigation to three different staff persons. Thus, for example, the staff member who talked to the youngsters did not talk to the staff. Fortunately, the Commission review found no evidence that staff had been negligent in supervising the youngsters. Our recommendations focused on eliminating the fragmentation of the investigation and the risks inherent therein. The facility revised policies to ensure the coordination of investigations under one staff person and secured training for selected staff members in interviewing, taking statements, and the preservation and interpretation of evidence.

❑ The Commission began monitoring a resident's care and treatment in May 1990, after she sustained various injuries resulting from multiple assaults on her by other physically aggressive clients on the unit of a downstate developmental center. In response, the resident was moved to another unit and placed on one-to-one supervision.

Follow-up information received from the facility indicated that the resident had been involved in eight incidents during a six-month period. Subsequently, a follow-up site visit revealed that, in contrast to the information provided to us, the resident had been involved in at least thirteen *additional* incidents during this six-month period. Although in some instances progress notes stated that incident reports had been filed, the Quality Assurance staff person had no record of these.

In response to the Commission's findings, the developmental center indicated that for a few months the facility had been "deficient in tracking incident reports." To ensure that the same or similar problems are not repeated, the Commission requested that the OMRDD conduct a review of incident reporting procedures at the facility. Significant problems were uncovered and the facility is working on remediation under close Central Office supervision.

❑ In contrast to the above cases are the findings of the Commission's review of incident reporting at a voluntary-operated community residence. Early in the year a resident had been involved in altercations with another resident which resulted in minor bruises. In response, the program separated the residents and provided the assailant with increased supervision, and introduced a monitoring system that included body checks of the victim, and documented all events which might lead to injury. Notwithstanding these actions, on one occasion the resident incurred a bruise to her stomach and on another occasion a bruise to her back. The family was fearful that the resident was being subjected to abuse.

Our review found that the agency conducted a prompt and thorough investigation of the events involving the bruise to the resident's back. The monitoring system provided clear documentation that the resident had fallen against a bookcase and a bruise consistent with this fall had developed the following day. The program found that the family had not been properly notified of the bruise and staff were retrained on the importance of prompt notification. Further, the monitoring system revealed that another resident had hit the woman and a bruise consistent with this event had emerged two days later. The system also provided data to confirm no unusual pattern or incidence of injuries during the past year.

From Sexual Abuse/ Exploitation

Investigation at Bernard Fineson D.C.

The repeated failure of Bernard Fineson Developmental Center (BFDC) to protect residents who did not have the capacity to consent to sexual activity from exploitation and to recognize the seriousness of these incidents by diligent reporting, investigating and implementing corrective actions led the Commission to review the handling of serious incidents at the facility for the previous six months. The review revealed:

- ❑ despite OMRDD regulations defining "sexual abuse" as any sexual activity among unconsenting clients, BFDC staff and administrators disagreed with or were confused about the need for determining whether adult residents had the mental capacity to consent;
- ❑ staff confusion over the meaning of "capacity to consent" contributed to decisions not to characterize sexual assaults and sexual abuse properly as serious incidents, to be reported internally and to outside oversight and law enforcement agencies;
- ❑ reported incidents were misclassified, resulting in inadequate scrutiny; and serious incident investigations were often cursory and did not interview relevant witnesses, leaving unanswered questions and unsupported conclusions; and
- ❑ Incident Review Committee activities at BFDC were deficient and no system existed to ensure implementation and monitoring for effectiveness of needed corrective actions.

> The seriousness of the allegations, which included rape and sodomy, combined with the persistent failure of a department facility to take appropriate action over an 18-month period to protect vulnerable residents, clearly demonstrated the need for guidance from the OMRDD.

Although at the Commission's urging, the facility had determined which residents of the sixth and seventh floors of the Corona Unit at BFDC had the capacity to consent to sexual activity and which did not, the review revealed that facility staff failed to understand their responsibility to protect those not capable of consenting from sexual exploitation. Office of Mental Retardation and Developmental Disabilities regulations §624.4(b)(2) specifically note that sexual activity among non-consenting adults constitutes sexual abuse — a serious reportable incident which must be reported to the OMRDD and the Commission, and investigated and reviewed by Incident Review Committee. Facility staff, however, believed these encounters were private matters between residents and chose to by-pass the incident reporting process.

The seriousness of the allegations, which included rape and sodomy, combined with the persistent failure of a department facility to take appropriate action over an 18-month period to protect vulnerable residents, clearly demonstrated the need for guidance from the OMRDD. Indeed, earlier in an April 1990 letter to the OMRDD Commissioner, the Commission described numerous instances across all residential and treatment settings, both state-operated and voluntary, of vulnerable persons with developmental disabilities who were not being protected from sexual victimization by other persons in the program.

Prompted by the Commission report on Bernard Fineson and convinced of the need to provide guidance to facilities as they balanced the dual responsibility of promoting the rights of capable adults while protecting vulnerable residents, OMRDD issued draft sexuality guidelines in December 1991.

The guidelines are divided into five parts and contain: 1) a preamble stating the need to ensure protection from harm while, at the same time, not denying or unduly restricting individual rights; 2) concepts related to the ability to consent to sexual contact; 3) indices for determining ability to consent; 4) concepts on protection and rights; and 5) legal background dealing with sexuality and sexual rights in New York State.

In addition to providing guidance to the provider community about sexual activity among persons with developmental disabilities, the Office of Mental Retardation and Developmental Disabilities also agreed to review the incident reporting process at Bernard Fineson Developmental Center and four other of its facilities. The facility also undertook a number of corrective actions to increase resident supervision, retrain staff in proper reporting procedures, enhance the quality of investigations and ensure the effective implementation of corrective actions.

Confusion Regarding Sexuality and Mentally Disabled Persons

The Bernard Fineson Developmental Center investigation and report may have been the Commission's most authoritative work during the report period in ensuring the protection and rights of mentally disabled persons, because it both touched on all aspects of incident review and underscored the need to develop and articulate a philosophy regarding sexuality which both recognizes the rights of competent developmentally disabled persons to control their sexual lives and the facility's responsibilities to safeguard vulnerable residents. It was, however, not our only work in this area. In fact, the Commission found confusion regarding sexuality and mentally disabled persons in all types of treatment settings. This confusion manifested itself in unclear or absent policies, in hesitation and faltering attempts to investigate allegations of sexual misconduct, and in failure to adequately supervise and protect residents not able to protect themselves.

☐ The Commission received two cases in one week concerning sexual activity on the adolescent unit of a metropolitan hospital. In response to concerns over the lack of documentation of daily unit activities and staff responsibilities, the poor quality of the facility investigation, delays in the reporting of the incidents, untimely physical examinations and the absence of guidelines for use of the Quiet Room, two Commission staff members conducted site visits. They interviewed administrative, clinical and direct care personnel and reviewed records.

In response to the Commission's investigation and recommendations, the hospital developed staff assignment sheets and patient observation checklists. The hospital also promised to formulate or revise policies concerning the use of PRNs and STAT medications; GYN examinations of children and adolescents; pregnancy tests, sex abuse examinations and the use of the "rape kit" with adolescents. In addition, three staff received Special Investigator training and additional staff were scheduled to participate in the next available training session.

☐ The Commission received an allegation that a 14-year-old patient had been raped by an adult male patient on the psychiatric unit of a medical center. (The State Central Register had not accepted the report.) The complainant independently reported the incident to the police and Mental Hygiene Legal Services (MHLS). MHLS notified the hospital and an investigation was initiated.

The medical center's investigation did not uncover any indication that the alleged rape had occurred. The investigation found, however, that neither the social worker nor her supervisor had received incident reporting training and, thus, the social worker had not properly reported the allegation. It also found that staff had not followed procedures in providing supervision to the residents.

The Commission's review of the Center's investigation found it inadequate. It did not fully explore the critical issue of staff supervision and failed to note that the matter had not been reported in a timely manner, either internally or to the Office of Mental Health. Further, the hospital had failed to respond to their Special Review Committee's recommendation to interview the patients (who were by then discharged) and they failed to address the finding that neither the social worker nor her supervisor had received training in incident reporting.

Based upon these inadequacies, the Commission conducted its own investigation. We found no evidence to question the veracity of the allegation and concluded that the alleged rape may have occurred as described. We discovered that nursing staff were aware that the allegation had not been reported and failed to generate their own report of the incident. We also found that staff routinely gathered in an office to complete paper work, leaving no staff on the floor during times patients were awake. Further, we found that the facility had no specific guidelines for investigations, nor mechanisms to ensure the accuracy and comprehensiveness of investigations.

We recommended that the hospital develop specific investigation procedures, including provisions for interviewing discharged patients; establish a mechanism for Special Review Committee monitoring of corrective actions; train/counsel staff regarding incident reporting; and, modify procedures to require some staff to be on the floor at all times when patients are active and awake.

In response, the hospital revised its investigation procedures, modified its practices to ensure staff presence on the floor during all "awake" times and provided training/counseling to its staff.

☐ Staff at a developmental center were extremely concerned about a young man whose family insisted he be given access to adult magazines and permitted to wear female clothing as an outlet for his sexual frustration, claiming these would reduce/prevent his sexual aggression. In contrast, staff observed that following home visits where the young man was given access to these articles, he was increasingly sexually aggressive.

The Commission recommended that staff clearly articulate the reasons for their fear and provide documentation of the young man's behavior, and that the facility secure an expert evaluation of this man's behaviors.

Armed with a strongly-worded opinion from the outside consultant, the facility staff instituted strict guidelines forbidding the resident access to sexually stimulating material and conversation and were attempting to engage the cooperation of the family in doing the same during the resident's home visits.

> We discovered that nursing staff were aware that the allegation had not been reported and failed to generate their own report of the incident. We also found that staff routinely gathered in an office to complete paper work, leaving no staff on the floor during times patients were awake.

☐ Terribly upset, a female patient at a state psychiatric center reported she had been raped by a male patient. The facility's investigation not only confirmed the rape, but also noted that the aggressor had sexually assaulted or attempted to sexually assault several other female patients over the course of his stay. With strong backing from the Commission and another OMH facility where the man had been a patient, the psychiatric center was able to have the man transferred to Mid-Hudson Psychiatric Center, a forensic facility. The psychiatric center also undertook measures to provide a safer physical environment and sensitize staff to issues related to victimization.

☐ In reviewing an allegation by a client of a day treatment program that a janitor was repeatedly sexually inappropriate with her, the Commission learned that similar allegations had been made by other women at the program. The program had virtually ignored the allegations, repeatedly citing the absence of witnesses as reason to take no action. The Commission directed the agency to undertake a full investigation of all of the allegations and provided technical assistance when needed. At the conclusion, the agency terminated the janitor and demoted the supervisor.

☐ A resident of a downstate ICF reported that she was being sexually abused by her father during home visits. The facility listened to the accounts but provided her no medical attention, did not call the police and continued to allow the home visits in response to the father's threat of a lawsuit and the family's request to keep the allegations private.

The Commission convinced the agency to call the police and to suspend home visits pending the outcome of the investigation. The Commission continued to monitor as the facility made substantial changes in its incident reporting and review process.

Beyond the Commission's role as an investigator/monitor, Commission staff spend considerable time providing technical assistance to agencies. It is common for facility administrators and quality assurance personnel to call the Commission asking for guidance on how to proceed in investigating a sexual incident or seeking advice on whether the protective and preventive measures they are initiating are adequate. Facilities also call when they need the Commission's intervention in securing the cooperation of another program or state agency, such as Adult Protective Services. The number of such calls is a testament to the desire of providers to appropriately handle what are serious matters, but which they are not comfortable discussing and exploring.

SAFEGUARDS

Among the actions taken by facilities to help them deal more effectively with sexual issues, the following have been noted by the facilities as particularly helpful:

- ☐ Revising sexuality policies so that they are easily understood by staff who will be called upon to enforce them.
- ☐ Conducting informal small group discussions with staff to help staff feel more comfortable talking about sexuality issues.
- ☐ Developing contacts with law enforcement agencies and child and adult protective services *before there is a crisis*. These contacts often can offer sound advice on how to proceed in certain situations.
- ☐ Reviewing the capabilities of residents to consent to sexual activity when this is in question prior to an incident, so that staff can be expected to react appropriately.
- ☐ Providing training for all persons, including those considered too disabled to consent to sexual activity, on saying "no."
- ☐ Including in the inservice curriculum material on the effect of prior sexual victimization on the personality and sexual development of individuals: what to look for and what to do when you see it.

Beyond the Commission's role as an investigator/monitor, Commission staff spend considerable time providing technical assistance to agencies.

FROM CHILD ABUSE

In fulfilling its mandate under the Child Abuse Prevention Act of 1985, during the report period the Commission investigated nearly 200 allegations of child abuse/neglect of children residing in facilities operated or licensed by the Department of Mental Hygiene. Statistics reveal that the majority of cases are alleged physical abuse of children by custodians and nearly 95 percent of the cases resulted in no or minor injuries to the child. The infrequency of findings of serious injury (requiring more than First Aid), imminent risk of harm and sexual abuse is heartening. It does not, however, tell the whole story. Much of the incalculable damage to children's ability to trust adults is symbolized by the minor injuries inflicted during "takedowns" and "wraps" and by the vulnerability inherent in inadequate supervision. While these are not grounds for "indication" of a case, they are nonetheless harmful and, in many cases, preventable.

An examination of the cases reveals several patterns of deficiencies which are amenable to correction at both the facility and Office level.

- ☐ Many of 133 physical abuse allegations occurred in the context of an inappropriate or misapplied physical intervention technique as the source of an injury. In a large number of these incidents, staff members had either not had physical intervention training or had not been retrained recently.

> The infrequency of findings of serious injury (requiring more than First Aid), imminent risk of harm and sexual abuse is heartening. It does not, however, tell the whole story.

- A review of the circumstances surrounding many of physical intervention incidents raises questions as to whether less intrusive calming techniques could have defused the situation if they had been tried earlier.
- The failure to take comprehensive abuse histories of the children, to explain the relevance of positive findings to direct care staff, and to modify supervision requirements and treatment plans have placed children at risk of sexual contact by other children.
- Unclear or unrealistic policies regarding the supervision of children contribute to staff's neglect of their duties to monitor youngsters.

As the cases below illustrate, a main focus of the Commission's work in its child abuse/neglect activities is not only making recommendations to DSS regarding the disposition of cases, but also the identification and remediation of factors which seed an environment where children are at risk.

- A 15-year-old in an RTF alleged he was choked during a take-down occasioned by the youngster's refusal to leave the TV room at 9:30 p.m. Staff witnesses saw no chokehold and the youngster sustained no injuries. Witnesses did confirm, however, that the dialogue which preceded the incident was inflammatory and contributed to the situation getting out of control. Specifically, when the youth refused the first request to get off the couch, the staff member approached him stating, "I'll just have to help you." He grabbed the youngster by the wrist and attempted to pull him upright. Within a matter of seconds, as the child resisted, the staff member was on top of the youngster lying on the floor.

  The facility agreed that this incident and several prior ones illustrated that the staff member lacked essential skills in dealing with adolescents and terminated the employee. The Commission recommended unfounding the case based on the lack of credible evidence of harm or risk of harm, which is a statutory requirement for "indicating" a case.

- A 15-year-old boy in a Children and Youth Unit of a psychiatric center made a similar allegation. The youth alleged he was hurt and choked during a physical intervention.

  When the youngster refused to stop tipping his dining room chair, then refused to go to the quiet room for the chair tipping, the staff member took the youth to the floor and pinned him using a Full Nelson hold. The youth was heard making gurgling noises, and his eyes bulged and then closed. When other staff stopped the intervention, the youth was unable to walk on his own, his voice was hoarse and his face blue. A nurse also observed petechiae (minute hemorrhages) on his face and eyes. The youngster could not recall the restraint on the next day because of anoxia (oxygen deficiency) occurring during the incident.

  The Commission recommended indicating the case and the facility had initiated disciplinary action. Sadly, we learned that no staff member on the Adolescent Unit on the night of the incident has completed Crisis Management training. The facility has undertaken to ensure that all Adolescent Unit staff members receive this training. To date, all but two staff have been trained and a train-the-trainer program has been completed.

- A school social worker called the State Central Register stating that an 11-year-old resident of an ICF had numerous body bruises and had lost twenty pounds over the past few months.

  An extensive review revealed that increased seizure activity (likely attributable to a growth spurt) and the consequent falls and bumps accounted for the bruises. The facility had documented these incidents and the youngster was under the care of a neurologist who was adjusting his medication. A physician was also monitoring the child's weight which had dropped six pounds in a year. No medical reason for the loss was identified and staff attributed it to the child's fussy eating habits. Staff were trying to give the youngster the foods he enjoyed while also coaxing him to try others.

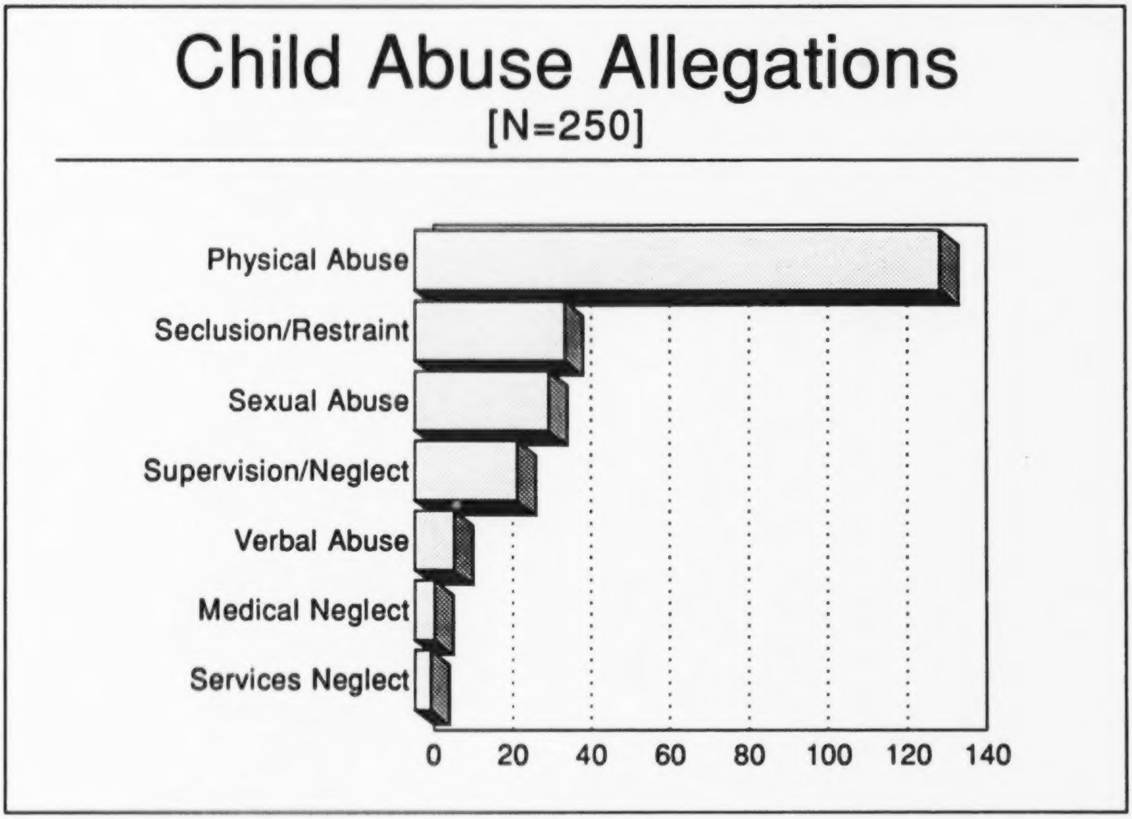
Clearly, communication between the ICF and the school was poor — a fact recognized by the ICF. Meetings were planned to develop a working relationship between the two staffs.

☐ On a Sunday morning in June, three adolescents residing in an RTF were playing outside the cottage under the supervision of a staff member. The three youths engaged in oral sex. One youth sneaked into an upstairs bathroom where he was joined by a second youth who was granted permission to use the bathroom. They continued their sexual activity there.

Five days earlier the treatment team had agreed that two of the three youths required increased supervision. The staff member supervising the children attended this meeting. When questioned, this staff member admitted he was not watching the youngsters and was either watching TV or making sandwiches in the kitchen. For his actions on the day in question and because of his failure to cooperate with the facility investigation, the staff member was terminated.

We pointed out that the facility had no definition of "increased supervision" and that the basic policy on supervision required that "staff must know the whereabouts of the youngsters at all times . . . they (children) must be within sight and sound of the staff on duty." This basic level of supervision was so demanding that it discouraged rather than encouraged vigilance.

The Commission recommended that the case be indicated. Equally important, we pointed out that the facility had no definition of "increased supervision" and that the basic policy on supervision required that "staff must know the whereabouts of the youngsters at all times . . . they (children) must be within sight and sound of the staff on duty." This basic level of supervision was so demanding that it discouraged rather than encouraged vigilance. The facility agreed


Child Abuse Allegations

[N=250]

with our observation and revised the supervision policy and definitions.

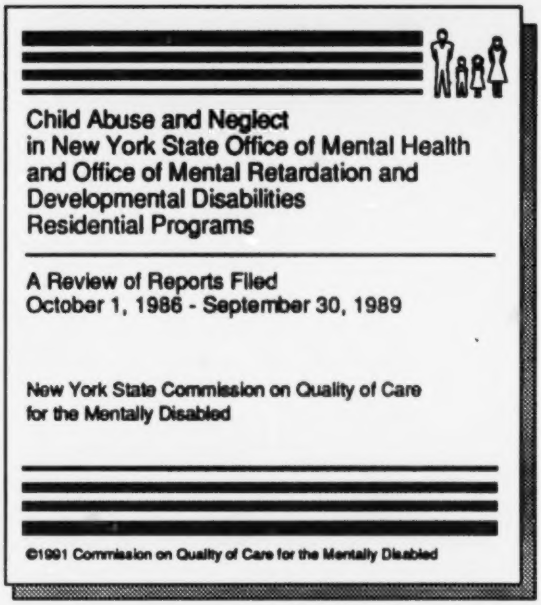
- An 11-year-old at a downstate Children's Psychiatric Center alleged that he was shoved against a wall and hit with an open hand by a staff member.

  The child was required to go to bed early because he had been verbally abusive and provocative to other children earlier in the day. According to patient witnesses, as the child stood in his doorway, the staff member pushed him into the bedroom and closed the door. By his own admission, the staff member threatened to place the child in seclusion if he did not move into the bedroom. The youngster alleged that the staff member hit him once inside. The staff member denied this. Several minutes later, the staff member and youngster reappeared and the staff member placed the youth into a locked seclusion room. When he could not find a nurse, he released the child after a few minutes.

  The Commission found a clear breach of duty in the staffer's actions and noted with concern the inappropriate threat of seclusion for behavior that was not dangerous to the youngster or others, which is required by OMH regulations and policy to justify seclusion. Since this was the second time residents reported these threats, the Commission asked the facility to review the matter. The facility found no evidence of widespread misuse of seclusion. The Office of Mental Health has undertaken a review of the facility's incident reporting procedures, including a review of the implementation of corrective actions.

From Institutional Child Abuse

Soon after the Commission assumed responsibility for conducting investigations into reports of alleged child abuse or neglect in mental health and mental retardation residential facilities pursuant to the Child Abuse and Prevention Act of 1985 (CAPA), the agency established a computer data base to track important issues and trends in these allegations. In the winter of 1991-1992, the Commission released a report, *Child Abuse and Neglect in New York State Office of Mental Health and Office of Mental Retardation and Developmental Disabilities Residential Programs*, based on data collected during the investigations of the 850 child abuse cases reported during the first three years of CAPA implementation (October 1, 1986 - September 30, 1989).



Child Abuse and Neglect
in New York State Office of Mental Health
and Office of Mental Retardation and
Developmental Disabilities
Residential Programs

A Review of Reports Filed
October 1, 1986 - September 30, 1989

New York State Commission on Quality of Care
for the Mentally Disabled

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Major Findings:

- The report highlights the significant group of 183 children who were cited in more than one report. Of note, 32 of these children were cited in four or more reports. Children cited in more than one report were more likely than other alleged victims to be over the age of ten (90% vs 77%), and non-white (58% vs 38%). The vast majority (92%) of repeat alleged victims resided in mental health facilities, and 77% resided in the state children's psychiatric centers or children's units.
- According to facility staff, over one-third of the incidents took place during "free time" when no activity was scheduled. Free time was especially likely to be associated with incidents alleging physical abuse (39 percent) and inappropriate restraint or seclusion (45 percent).
- Only 13 percent of the incidents occurred during recreation, school, or other scheduled programs when professional staff were most likely to be present.

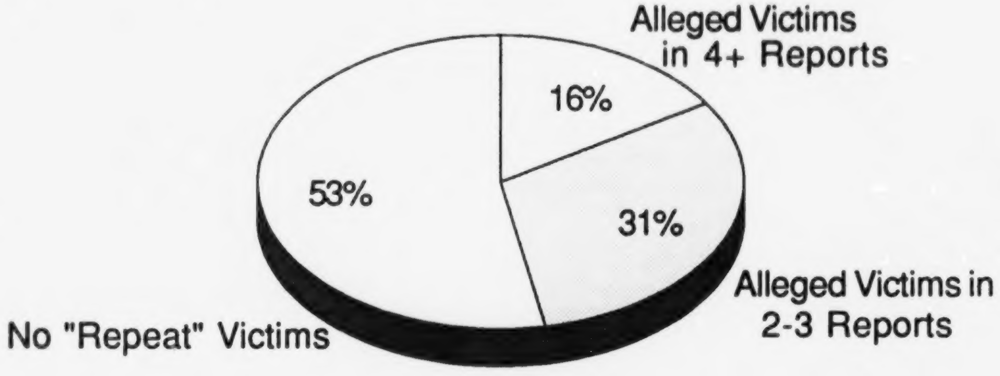
- ☐ Nearly one-fourth of the reports (22 percent) alleged the inappropriate restraint or seclusion of children, and the circumstances of over half of the reports (55 percent) related incidents where staff were trying to control problem behaviors of children.
- ☐ The Commission recommended indication (confirmed abuse) to the New York State Department of Social Services (DSS) in one-fourth (24%) of the reports, with reports filed by mental retardation programs having a significantly higher indication rate than reports filed by mental health programs (33% versus 22%).
- ☐ Although only 24% of the reports were recommended for indication, the Commission made specific recommendations to the reporting program in over half of the cases (58%). In nearly one-fifth of the reports, recommendations were made pursuant to the providers' reporting and investigation practices; in nearly one-fourth of the reports, recommendations centered on other administrative practices; and in 16% of the reports the recommendations urged increased staff supervision or training.

RECOMMENDATIONS

In addition to case-specific recommendations, the Commission's report also discusses specific recommendations designed to add to the safety net for children residing in mental hygiene facilities, including:

- ☐ Enhanced training of facility professionals, family members, and children to promote prompt reporting of possible allegations of institutional child abuse and neglect;
- ☐ Clear requirements for regular clinical staff presence on living units during all times when children are present, including evenings and weekends;
- ☐ Greater attention and protection for children who appear as subjects in two or more reports of abuse and neglect to the State Central Register;
- ☐ Increased use of more effective, non-physical methods for intervening with children whose behavior is problematic or dangerous;
- ☐ Limiting extended periods of "free time" on residential units in the late afternoons and eve-

Percent of Reports by Presence of "Repeat" Victims
(Oct '86 - Sept '89)



(N = 850)

nings, especially when clinical staff are not present on the unit;

- ☐ More accountable facility and OMH/OMRDD procedures to ensure correction of problems identified during child abuse and neglect investigations by making such compliance a condition of facility's continued certification.

RESPONSES

In its response, the Office of Mental Health concurred with the recommendations and expressed the particular intent to strengthen efforts to identify and review "repeater" and "high risk children" based on the report findings and to improve training efforts in the area of child abuse reporting and follow-up.

The Office of Mental Retardation and Developmental Disabilities also agreed to address the problem of "repeater" and "high risk children." OMRDD will work with the Commission to identify these children and evaluate their needs, and will implement a monitoring mechanism to ensure that other children who may have similar problems are identified by staff. Through training and other means, OMRDD will address the problems of underreporting and lack of quality reporting in the incident review process.

FROM FINANCIAL EXPLOITATION

In the face of the state's deepening fiscal crisis and continuing national recession, the Commission has been especially focused upon its statutory obligation [N. Y. Mental Hygiene Law §45.07] to protect the fiscal integrity and cost-effectiveness for delivery of services to those most in need. Therefore, Commission fiscal investigations were directed, during this reporting period, at eliminating profit-making abuses in the system of care and at protecting the public purse while preserving scarce dollars for meaningful services.

ADULT HOME AUDITS

In October 1990, the Commission released its report on *Adult Homes Serving Residents with Mental Illness: A Study of Conditions, Services, and Regulation*. A major finding of the report was that, despite the massive amount of public financing for adult homes, the State Department of Social Services (DSS) has never attempted to determine how actual expenditure of the public monies by licensed facilities might explain the underlying poor conditions at a large number of homes. Indeed, the Commission found that, since 1979, DSS has neither exercised its statutory authority to conduct a fiscal audit of even one adult home, nor appropriately

THE NEW YORK TIMES **METRO** *THURSDAY, FEBRUARY 13, 1992*

Wide Use of Force on Disturbed Children is Found

By CELIA W. DUGGER

Poorly trained workers in institutions for emotionally disturbed children in New York State all too often handle disruptive behavior by putting youths in locked rooms, straitjackets or padded wrist cuffs, or controlling them through other kinds of physical force, a state report released yesterday concluded.

The New York State Commission on Quality of Care for the Mentally Disabled found that workers with little more than a high school education were left with disturbing frequency to monitor children at night and on weekends when professional staff members went home.

"If the staff are not trained to defuse a situation and calm a child, they often resort to physical restraints," said Clarence J. Sundram, chairman of the commission. He cited straitjackets, padded wrist cuffs and sheets that immobilize a child in bed from the neck down.

The report by the commission, which is appointed by Gov. Mario M. Cuomo, is based on reports of abuse and neglect involving 823 children in state-supported public and private institutions between October 1986 and September 1989.

No Blame, No Case

Only a quarter of the reports were confirmed, but that proportion underestimates the magnitude of the problem, the commission cautioned. In many cases, investigators found that a child had been neglected or abused, but could not determine which worker was to blame. Under state law, those reports are not counted as confirmed cases of institutional child maltreatment.

Almost one-fourth of the reports involved improper use of seclusion or restraining devices to subdue unruly children, the study found.

Officials at the state Office of Mental Health acknowledged the problem. "We need to work with staff to develop alternative ways of dealing with children so the use of physical restraint is unnecessary or decreased," said Gloria Newton-Logsdon, associate commissioner for children and families.

Dr. Newton-Logsdon said the agency was trying to make sure that there are more nurses and therapists working evenings and weekends, when children have more free time and more often get into trouble. . . .

BEST COPY AVAILABLE

utilized its enforcement powers to compel specific performance of improvement at homes with serious problems.

Studies of the nursing home and adult home industries by Special Prosecutor Charles J. Hynes over a decade ago uncovered a basic technique to increase profit-making for operators and their families, namely, to control the ownership and leasing of the facility's property and to enter into non-arm's-length dealings which artificially inflates rent and accordingly diverts that income to related parties. These arrangements create higher "costs" that are in reality hidden "profits" which usually go unnoticed to related parties under different corporate or individual names, but do not go into resident care. Given this history, the Commission sought to examine the finances of one home with poor conditions visited during its legislatively mandated study to see if this was occurring there.

HI-LI MANOR HOME FOR THE AGED

The purpose of the Commission's inquiry into the finances of the 125-bed HI-LI Manor Home for the Aged, a DSS-licensed "not-for-profit" adult home in Far Rockaway, New York, was to obtain reliable information about the operating costs of this home to understand the reasons for its obviously deficient care and problems in its basic living conditions. Efforts to accomplish this objective were seriously delayed by protracted challenges to the Commission's right to access records, noncooperation, chaotic or missing records, and noncompliance with judicial orders. Despite these obstacles, a picture is emerging which is sadly reminiscent of the findings at adult and nursing homes by the Special Prosecutor in the 1970s.

As this report goes to print, the Commission's two-year investigation is reaching a conclusion. The Commission expects a public report on the finances on this home in 1992.

SPENDING ABUSE REFORM

As with the Commission's outpatient mental health services study which led to major structural reform, past Commission in-depth reviews of the spending practices of problematic mental health providers (e.g., Brooklyn Psychosocial Rehabilitation Institute Inc.; New York Psychotherapy and Counseling Center) have led to closer scrutiny and control over the delivery of community-based services. Most notably, responding to the Commission's concerns about the potential for fiscal abuse, the Office of Mental Health and the Department of Social Services embarked on a two-year joint auditing project to determine how reflective were the Commission's findings of provider practices. In a July 1991 OMH Auditors' Progress Report, it was concluded that "the types of problems uncovered by the Commission, as well as other problems, all of which involve the influx of state funds and/or the inappropriate use of such funds, are widespread."

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Not unlike the Commission's findings on profit making abuses, these audits revealed cases of Medicaid abuse (to make funds available for personal use); self-dealing in real estate; excessive executive compensation; luxury automobiles; large life insurance policies for senior executives; and, other perquisites and practices which were inconsistent with the agencies' not-for-profit status. Certified cost reports and financial statements which were long thought to be a check on errant behavior were similarly found to be an unreliable solution because of inaccurate or manipulated documents. Given these abuses and the increasing pressures to control the cost of spiraling patient care, the Commission, in conjunction with state regulatory agencies, initiated actions on a number of fronts.

CHARACTER AND COMPETENCE

One aspect of regulating the community-based system of care for the mentally disabled is the investigation of the qualifications, background and suitability of individuals seeking licensure. Prompted by its experience with problem providers, the Commission conducted a management survey of the systems used by the four DMH agencies (OMH, OMRDD, DAAA, DSAS) to assess the "character and competence" of prospective licensees. The Commission found substantial deficiencies and unexplainable differences in all the systems when measured against the comprehensive system of the Department of Health, which was put into place after the nursing home scandals of the 1970s.

An assessment of the Commission's findings by the Governor's Office of Management and Productivity confirmed that there were such serious weaknesses in the license application and renewal process of the DMH agencies, and thus the Commission's survey was instrumental in bringing about a series of significant improvements. For example: (1) DSAS has revamped its entire system for licensing and has expanded its reviews to include board members and the personal histories of applicants, (2) DAAA and OMH now examine the character and competence of senior executives in addition to board members, and (3) OMH and OMRDD now require that applicants certify to the truthfulness of their applications, which would be essential for any subsequent state enforcement actions.

PROFESSIONAL MISCONDUCT BY ACCOUNTANTS

Following referrals to the State Education Department's Office of Professional Discipline, in 1991 two accountants involved in the cover-up of profit-making abuses at the New York Psychotherapy and Counseling Center (NYPCC) pled guilty to charges of professional misconduct. In the first case, a certified public accountant with the firm of Loeb & Troeper pled guilty to a charge of failing to identify and disclose transactions for rental and purchase of agency buildings that were less-than-arm's length. He agreed to an $8,000 fine and another penalty of official Censure and Reprimand. The basis for the charges was the Commission's December 1989 NYPCC report, *Profit Making in Not-for-Profit Corporations: A Challenge to Regulators*, which revealed that the officers of NYPCC, ostensibly a not-for-profit corporation, were able to benefit by $720,000 from rental payments and capital gains through their joint control of NYPCC and for-profit reality businesses. Despite its officers' claims, it is very questionable whether NYPCC needed their financial assistance in acquiring or leasing the agency properties they benefited from.

In a second guilty plea, a public accountant had issued opinions on NYPCC's finances as an "independent" auditor, while serving as a board member and president of the agency, and also without performing any necessary auditing procedures. He agreed to a $1,000 fine and partial suspension of his license in the auditing area until he completes continuing education on how to conduct an audit.

The Commission believes that accountants who fail to live up to the standards of their profession should be barred from preparing financial reports for any state-licensed facility because such audits are in fact relied on by state mental hygiene licensing agencies. Legislation to disqualify such accountants from preparing these reports is pending at the Commission's recommendation.

COURT UPHOLDS STATE'S BILLING REGULATIONS

The Commission's 1989 investigation of NYPCC also exposed its practice of misrepresenting group therapy sessions as if they were individual therapy to receive the higher reimbursement rate in violation of OMH regulations, generating millions of dollars in improper billings. OMH acted upon the Commission's findings and ordered this practice to cease immediately, but NYPCC sued OMH for a declaration by the State Supreme Court that NYPCC's billing practice was legal and had indeed been authorized by an OMH official. In a 1991 decision, the Court granted a declaratory judgment in OMH's favor which should clear the way for a recoupment action by DSS against NYPCC for $2.6 million of improper Medicaid billings from 1986 to January 10, 1990, when NYPCC was directed by OMH to cease its "enhanced billing" practice.

The court ruled that a state agency subordinate cannot authorize billing practices in violation of state law or regulations. Otherwise, agents of the state operating outside the law could "easily result in large scale public fraud." Although the above suit was nominally against OMH, it stemmed from the Commission's 1989 report which found NYPCC executives improperly benefiting through excessive salaries and other remuneration, rental income and capital gains, by less-than-arm's-length transactions with a family-owned realty entity, and by donations to charities with which the executives were connected.

U.S. TAX COURT RULING SUPPORTIVE OF COMMISSION CHARGES THAT "NOT-FOR-PROFIT" BPRI WAS OPERATED FOR PERSONAL GAIN

On September 23, 1991, the U.S. Tax Court confirmed contentions by the Commission's 1986 investigation that, through his behind-the-scenes control of the Brooklyn Psychosocial and Rehabilitation Institute, Inc. (BPRI), its part-time medical director converted it into a profit-making enterprise for himself and his family. The Tax Court found that the transfer of the business operations of his wife's community residence was motivated by the medical director's desire to obtain additional public revenue unavailable to their proprietary business. Because he "controlled the parties on both sides" of the lease, he was able to devise a plan to reap millions of dollars from inflated rental payments and from the increased public revenue by simultaneously being the landlord of the BPRI facilities and its tacit, unofficial CEO.

The Tax Court reduced charitable deductions claimed on his joint income tax returns that were based on an inflated $680,120 value of the business transfer related to "profits" from increased government funding. Instead, it allowed deductions on a lower $145,416 "going concern" value.

SUIT AGAINST STATE OFFICIALS DISMISSED BY U.S. COURT OF APPEALS

On October 18, 1991, the U.S. Second Circuit Court of Appeals affirmed the District Court's July 18, 1990 dismissal of a federal civil rights lawsuit (*Easton v. Sundram et al.*) against state officials from the Executive Chamber, OMH, Office of the Attorney General, and the Commission seeking $60 million in damages for an alleged "secret conspiracy" to remove the operators of BPRI, previously the largest community residence for the mentally ill in the state, and deprive a former mental health provider of his property and livelihood. The court totally dismissed these claims without a hearing because they were baseless and because of the legal immunity of state officials.

The suit was initiated by the former BPRI medical director against state officials who investigated, prosecuted or testified against him in a state proceeding (*People v. BPRI et al.*) charging him — as medical director and *ex officio* board member of the not-for-profit BPRI — with Medicaid fraud, endangering the health and safety of residents and siphoning public funds through BPRI to members of his family by way of improper leases with real estate corporations owned by his children. The medical director alleged that the Commission's 1986 investigation of suicides at BPRI and its subsequent fiscal review, and all of the charges that stemmed therefrom, were fraudulently concocted and presented in bad faith. Although the state received an adverse decision by a Judicial Hearing Officer in a civil case that sought $9.3 million in trebled damages for Medicaid fraud and real estate abuses by the medical director and his family, an appeal to the State Appellate Court has been filed seeking a reversal of this decision.

FISCAL REFORM LEGISLATION

Responding to profit-making abuses in the mental hygiene system, the Commission was successful in having legislation enacted during the 1991 Legislative Session which (1) prohibits the DMH-licensed agencies from using state aid, SSI, or Medicaid funds for charitable contributions [§§16.32, 21.15, 23.15, and 31.31 MHL], (2) requires senior executives of DMH-licensed agencies entering into less-than-arm's-length real property transactions to disclose the material facts of the transaction in writing to their boards of directors and to the DMH commissioners as a condition for public funding [§41.46 MHL], and (3) requires board approval of any property leases for all state not-for-profit agencies [§509 N-PCL].

Other fiscal reform legislation contemplated by the Commission in conjunction with the DMH agencies includes (1) using past fiscal management performance in the criteria used to evaluate the character and competence of a prospective licensee, (2) placing reasonable limits upon salaries of "not-for-profit" mental hygiene providers, (3) prohibiting loans of corporate funds to senior executives of licensed agencies, (4) requiring disclosure of related party dealings with licensed providers by officers and senior executives of the agency, and (4) establishment of a central registry for accountants preparing financial or cost reports relied on by the DMH agencies

During this difficult, yet challenging period, the Commission continues its advocacy functions in responding to, caring for, and helping individuals with disabilities in specific problems and situations, and providing legal assistance and education through the protection and advocacy networks.

OPPORTUNITIES: THE CHALLENGE TO CHANGE

Despite the climate of recession and budgetary restraints, hard times also present unique moments of opportunity to undertake fundamental reforms that may not be possible without an atmosphere of crisis. In these times, the role of advocates requires that we both assure the protection of the interests of people who are vulnerable and, at the same time, recognize opportunities for change.

As just one example, there is growing consensus on the importance of consumer empowerment and choices; yet, the menu of options is limited by an historic overreliance on expensive institutional services, which are also often inappropriate. The challenge to advocates is to find opportunities where the interests in quality, appropriateness, and cost-effectiveness are consistent, and to promote such public policies.

During this difficult, yet challenging period, the Commission continues its advocacy functions in responding to, caring for, and helping individuals with disabilities in specific problems and situations, and providing legal assistance and education through the protection and advocacy networks. We continue to promote quality of life and services by our monitoring of deaths, and advance fiscal and policy change initiatives based on our experiences and history in monitoring and advocating for people with disabilities.

DC CLOSURES

The Office of Mental Retardation and Developmental Disabilities has a stated goal of closing all developmental centers by the end of this decade or early in the next. The Commission has been engaged in a variety of activities with the Office of Mental Retardation and Developmental Disabilities both supporting the closures and working for new policy directions in creating living and working options for persons with developmental disabilities in the community. In these efforts, the Commission has advocated consistently for greater attention to consumer choice and involvement in decision-making for community living. The Commission has also encouraged a re-evaluation of how past development policies have ultimately impacted on the opportunities of persons with developmental disabilities to be included, not just placed in local communities.

These efforts have included:

☐ Support for the expansion of the planned use of the Home and Community-Based Waiver to all regions of the state in planning community services to replace the institutional services of state developmental centers.

☐ Targeted advocacy for increased reliance on small community-based residential options for 1-4 persons in the place of the larger 8-12 community-based ICF-MRs and residences that had been the mainstay of the state's development over the past few years.

☐ Participation in the closure advisory committees for Wilton Developmental Center, and supporting community advocates in their call for smaller residences and day programs and more consumer and family choice in developing truly individualized community service plans for each individual moving from the center to the community.

☐ Creating a forum for consumer, family member, and advocate commentary on developmental center closures and the opportunities and challenges they present through publication of a special edition of the Commission's newsletter.

☐ On-going reviews and comments on state regulatory and planning proposals for closure and the implementation of the Home and Community-Based Waiver, which provided repeated opportunities to support and reinforce values of individual choice, normalization, quality of life issues, and person-based quality assurance.

FISCAL REFORMS

Because of the Commission's historical experience in scrutinizing the expenditure of public funds, it has been able to put forward a series of policy and legislative changes to control costs and/or maximize federal reimbursement without seriously affecting programmatic availability or quality. Indeed, one of the Commission's major fiscal recommendations to reduce voluntary agency dependence on state and locally financed "net deficit" funding by substituting these funds with Medicaid revenue led to a major restructuring of community-based outpatient services for the seriously mentally ill. Another study recommendation concluded that funding increases for adult homes serving a significant number of residents having a mental disability be targeted to only those providers that exceed minimum standards in delivering quality services to its residents. Still other fiscal reform initiatives were directed at eliminating profit-making abuses in the community-based system of care (See above, pp. 26-29).

REFINANCING AND RESTRUCTURING OF OMH OUTPATIENT SERVICES

Among the findings in the Commission's July 1989 *Outpatient Mental Health Services* report was that 95 percent of state-operated or licensed psychiatric outpatient programs were clinically oriented. Yet, federal reimbursement under the medical assistance program or Medicaid, which was offered as an explanation for New York's heavy clinical orientation, played only a minor role in its financing. Indeed, less than 13 percent of the almost $800 million spent for outpatient services in 1986, the most recent year for which data was available in the study, was reimbursed by federal funds, which meant that the state and its local governments were financing much of the services—even though the Medicaid was a potential source of funding. The state and local governments were financing almost a quarter of a billion dollars a year in net deficit funding, to a large extent because Medicaid fee schedules that were not cost-based generated too little income to cover program costs. At the same time, despite its size and significant cost, the state had not articulated requirements for services to persons with serious and persistent mental illness causing an over reliance on costly psychiatric hospitals.

Responding to the Commission's concerns, the 1991-92 *Executive Budget* recommended and the

Actual "hard dollar" savings from the Commission's recommendation are estimated to be $15 million for the state and $9 million for localities.

Legislature agreed to a reimbursement methodology which substantially reduced licensed agency dependence on net deficit financing by replacing these funds with Medicaid revenue. The program to change the financing of outpatient services requires that local providers enter into a formal agreement with the Office of Mental Health to establish comprehensive outpatient programs (COPS) to serve the most seriously mentally ill individuals and to promote planning and coordination at the local level. Special emphasis is placed on priority services (e.g., 24-hour emergency care) to persons referred from inpatient or emergency settings. Thus, this funding initiative, which forestalled potentially devastating program reductions, was used to promote a better and more responsive service system while relieving some of the pressure on hospital emergency and inpatient services.

The refinancing methodology, in the aggregate, provided $53 million in increased Medicaid reimbursement, which was used to reduce state and local financing (a mix of county funds and voluntary contributions) of provider agency deficits by the same amount. Because the state and localities are required to finance the approximately 55 percent non-federal share of Medicaid, actual "hard dollar" savings from the Commission's recommendation are estimated to be $15 million for the state and $9 million for localities.

ADULT HOME FINANCES

The Commission's October 1990 study on adult homes found, from examining the correlation between expenditures by the homes and their conditions, little difference in overall expenditures between the homes with better or poorer conditions. It found in this industry of mostly proprietary facilities a constant tension between the obligation to provide quality care and the legitimate desire to make a profit. Moreover, the flat rate Supplemental Security Income (SSI) funding to the homes offered no real incentive to meet or exceed minimum standards; to the contrary, there has been a financial advantage to not meeting them. In fact, in a flat rate system of profit-making services there is a perverse incentive to skimp on care as a means of increasing profits. Thus, absent meaningful enforcement of regulatory standards, it should not be surprising that many homes looked at by the Commission did not meet minimum staffing standards and consistently failed to invest in repairs and maintenance.

While almost all homes had bottom line profits, examination of the industry's real "profitability" had not been possible without the submission of balance sheet financial statements and comprehensive audits of home finances which could disclose true costs of operation and profits. For these reasons, the Commission concluded there was no clear basis for recommending an across-the-board increase in SSI reimbursement levels. Instead, the Commission is urging for the subset of 150 adult homes with 25 percent or more persons with a diagnosis of mental illness the creation and funding of a Quality Improvement Program, which provides financial incentives to providers to exceed minimum standards in delivering quality services to its residents. This reimbursement approach would provide additional cash payments beyond the SSI rate for exceeding standards in specifically defined areas such as physical environment, resident participation in programs and activities, quality of personal care, resident satisfaction or other valuative measures.

As a result of this study, DSS is now requiring homes to submit balance sheets to understand the underlying profitability and fiscal viability of this industry.

PREVENTING DEATHS AND PROMOTING QUALITY OF LIFE

Mental Hygiene Law (MHL § 45.15) mandates that the Commission review circumstances surrounding the deaths of persons who receive services from state-operated and licensed mental hygiene outpatient and residential treatment facilities, and investigate all deaths which appear to be due to unnatural or unusual circumstances.

Official reports of the Mental Hygiene Medical Review Board's findings are sent to the facility director and the Commissioner of the State Office of Mental Health or Mental Retardation and Developmental Disabilities. According to statute, these individuals are required to respond to the Commission's recommendations within 90 days of the receipt of the report with plans of actions to correct individual deficiencies as well as to implement systemic changes.

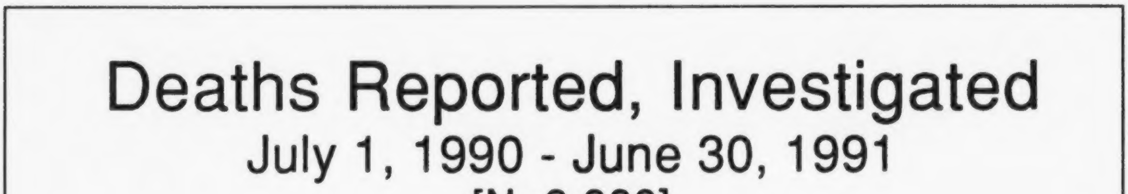
Case Examples:

- In reviewing the death of a child residing in a facility dedicated to serving medically frail developmentally disabled persons, the Commission found that, when the young girl experienced respiratory distress, an internal emergency code was immediately called and facility staff, including a physician, promptly responded and initiated CPR. However, nearly an hour elapsed before facility staff called for an ambulance to transport the child to a hospital where she subsequently expired. In its internal review of the death, the facility concluded that the delay in calling for transport to a community hospital was not inappropriate, as CPR was being rendered. The Commission, however, in its report of findings, recommended, and advocated, that in acute medical crises—such as this one—emergency services should be called immediately to ensure the client is promptly transported to a hospital where aggressive medical attention in fully equipped and staffed emergency rooms can be rendered. Consequently, the facility revised its policies to require that 911 be called and transfer to an acute care hospital be effected immediately for clients needing emergency care.

- A 66-year-old patient of a psychiatric center died as a result of peritonitis. Upon autopsy it was found that his duodenum had been perforated by a foreign object and his stomach contained many inedible objects including straws, surgical tape, pieces of styrofoam cups, etc.

  The Commission's investigation revealed that this gentleman had a long history of PICA behavior—eating inedible objects—which, while known, was not adequately addressed by his treatment team. In response to the Commission's findings, the facility established a Task Force to develop guidelines for the effective treatment and management of patients who exhibit PICA behavior.

- The seizure-disorder related death of a 39-year-old mentally ill resident of an adult home raised concerns about the integration of services for the home's residents and communication among their service providers.



Deaths Reported, Investigated

July 1, 1990 - June 30, 1991

[N=2,288]

> The Medical Review Board communicated its findings and concerns about the performance of these health care facilities to the Department of Health, which confirmed the Board's conclusions and required both hospitals to take appropriate corrective actions.

The Commission's review of this death found that although the resident, who had a known seizure disorder, reported increased seizure activity to the mental health team stationed in the adult home, this information was not communicated to the private physician retained by the home to treat its residents. Nor was it reflected in records maintained by the case manager employed by the adult home. Consequently, the increased seizure activity was neither assessed nor treated, prior to the resident's death.

In response to the Commission's findings, the Department of Social Services, which oversees the operations of this adult home, reported that it has required the home to convene regular meetings of both on-site and off-site service providers to share relevant information about the facility's residents, and revised record keeping practices to improve communications among service providers.

- The Medical Review Board's findings concerning the death of a 37-year-old resident of a community based ICF prompted the residential program to revise its procedures on infectious disease precautions, communication with physicians, and securing hospitalization for acutely ill patients.

In the summer of 1990 the ICF resident developed what was believed to be chicken pox. A physician was consulted who ordered that the client remain isolated at home—a difficult task in a group home setting. As days went by, the resident's condition worsened; his body was covered with lesions and he became dehydrated. During the weekend preceding death, residential staff believed the client needed hospitalization and tried several times without success to contact the agency's physician.

On Monday morning the physician was contacted and ordered a transfer to the hospital. The resident died shortly thereafter of a pneumonia associated with chicken pox.

To remedy the problems cited by the Medical Review Board, the agency established or revised policies to ensure that:

— Clients requiring isolation due to infectious diseases are admitted to the hospital;

— An agency's physician will be available 24 hours a day to respond to calls for assistance; and

— Staff promptly send clients to the hospital if a physician cannot be contacted and it is believed that a client's condition warrants hospitalization.

- A Commission and Medical Review Board investigation into the death of a family care client who received severe burns in a bathtub revealed that the client had suffered the burns accidentally and that the care provider immediately sought medical attention.

However, it was also found that the client was inappropriately denied admission to a Regional Burn Treatment Center, and received less than adequate care in a community hospital to which she was eventually admitted. The Medical Review Board communicated its findings and concerns about the performance of these health care facilities to the Department of Health, which confirmed the Board's conclusions and required both hospitals to take appropriate corrective actions.

- A 38-year-old patient with a known history of having a seizure disorder and polydipsia (excessive water intake which can result in electrolyte imbalance causing seizures) died suddenly at the psychiatric center where he had been treated for one and one-half years. The Medical Examiner's Office determined that the death was the result of a seizure.

In reviewing this sudden death the Commission found that, although the patient was referred for a neurological work-up shortly after admission, he never received one. Additionally, it was found that the patient's care plan called for limiting his water intake; however, there was little documentation concerning how this was monitored, and it did not appear that the patient's sodium and other electrolyte levels were aggressively monitored.

In response to the Commission's findings, the facility issued directives to medical staff calling for prompt neurological consults for all patients admitted with a history of neurological dysfunction and follow-up every six months; weighing patients daily who are on water restrictions; and testing sodium levels of patients on water restrictions on a monthly basis, and flagging and aggressively treating and monitoring patients whose serum sodium level falls below a certain point.

- ❑ In response to Commission and Medical Review Board investigations into the death of two patients who committed suicide while on leave from two psychiatric centers, the involved facilities agreed to change practices concerning the granting of leaves or passes. In the cases investigated, the Commission and Board concluded that the deaths were not predictable. However, noting the therapeutic value, as well as risks, involved in granting patients passes to leave facilities, the Board opined that it would be desirable to grant the leaves or passes after a full treatment team discussion and to document the discussion. The Board also recommended that treatment teams assess and document how well patients manage, or respond to, their leaves and passes, particularly when these privileges are initially granted to patients. The involved facilities concurred with the Board's suggestions and revised their policies accordingly.

- ❑ A Commission and Medical Review Board investigation into the traumatic death of a patient recently discharged from a psychiatric center underscored, for the involved facility, the need for careful attention to the unique needs of patients at the time of discharge and caution in making changes in patients' plans for aftercare.

  The 31-year-old patient had a long psychiatric history marked by multiple psychiatric hospitalizations and non-compliance with outpatient services. His problem with non-compliance with outpatient care prompted the assignment of an Intensive Case Manager (ICM) who successfully escorted the patient to outpatient appointments, conducted home visits and maintained contact with the patient three times a week.

  In the summer of 1990, the patient required rehospitalization. During the hospitalization, he lost his apartment and new housing was found. However, it was in a different catchment area than he had lived previously and would require that he be referred to a new outpatient clinic upon discharge. At the time of discharge the patient's ICM was on vacation. Nevertheless, the patient was discharged with an appointment to attend an outpatient program which he had never before visited.

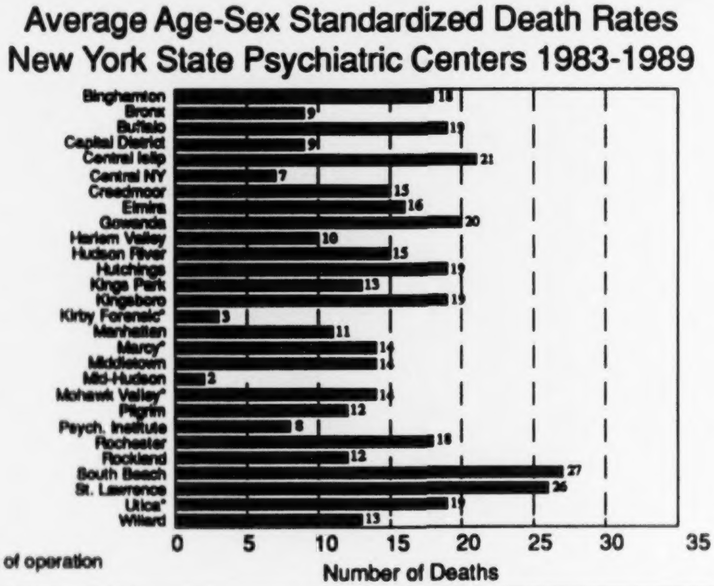
> The Commission and Board felt that, given the changes in the patient's life—new housing, referral to a new outpatient program, the temporary absence of his faithful and effective case manager—greater caution should have been exercised in planning his discharge.

  The patient never made contact with his outpatient program and fell to his death. It was undetermined whether the death was an accident or a suicide.

  The Commission and Board felt that, given the changes in the patient's life—new housing, referral to a new outpatient program, the temporary absence of his faithful and effective case manager—greater caution should have been exercised in planning his discharge. The facility agreed that to ensure continuity of care they and co-providers will carefully evaluate the wisdom of planning program changes for poorly compliant patients when intensive case managers are absent.

- ❑ In reviewing the death of an elderly psychiatric center inpatient who suffered, and died from, gangrene of her hip, the Commission and Board found that nursing and medical staff of the facility failed to provide timely and appropriate medical care when it was first noted that the patient had decubitus ulcers, or in the nearly four weeks which followed. In the absence of appropriate care, the patient's condition worsened to the point that, by the time she was transferred to a community hospital, amputation was the only remaining option. However, the prognosis for successful intervention and recovery was extremely poor and, at the family's request, surgery was not performed and the patient expired.

  In view of their poor performance, the Commission referred the involved nurses and physician to the appropriate licensing agencies for further review.



Average Age-Sex Standardized Death Rates
New York State Psychiatric Centers 1983-1989

*Avg. based on years of operation

ANALYSIS, FINDINGS IN DEATH RATES AMONG NYS PSYCHIATRIC CENTERS

The Commission conducted an analysis of deaths in New York state-operated psychiatric centers that occurred during 1983-1989. The research was possible because of legislation in New York which provides for the reporting of all deaths in mental hygiene facilities to the Commission.

The study revealed a preliminary linkage between high admission rates and high death rates, and found significantly lower death rates at some state psychiatric centers where improvements in first aid and emergency medical training were made.

This research identified a profile of the persons who died in New York State psychiatric centers during the period, and illustrated the causes of death. Analytical procedures of the study included the calculation and analysis of the variation in age-sex standardized death rates across the centers over the seven-year period, and an evaluation of center administrators' self-reports of factors potentially influencing the death rates across the centers.

During the period 1983-1989 widely varying annual death rates showed an overall decline from 16 to 12 deaths per 100,000 "bed days." The study determined that once facility death rates across the state's 28 psychiatric centers were adjusted for differences in the age and gender distribution of their populations, the number of annual admissions emerged as the single significant factor associated with death rates at the facilities. High admission rates, which tax staff time, stretch staff-to-patient ratios, and reduce care and attention available for individual patients, were found to be significantly related to high death rates.

Additional analyses also found that managerial and other staff changes, as well as the increased medical needs of the population served, did *not* significantly differentiate facilities with high death rates from facilities with low death rates. Only one facility characteristic—the implementation or improvement of training programs for basic first aid emergency medical treatment—was significantly associated with lower average death rates. Interestingly, the introduction of these training programs had been recommended by the Commission and the Mental Hygiene Medical Review Board as a result of a number of individual death investigations conducted during 1981-1985.

Although preliminary in nature, this research highlighted an important relationship between admissions and deaths, and provided empirical support for the theoretical recommendation that staff training in basic first aid and emergency medical treatment is essential to quality of care. This study also demonstrates the value of utilizing mortality data to examine patterns of deaths and develop strategies to avoid future deaths in state psychiatric centers.

RESPONDING, CARING, HELPING

QUALITY ASSURANCE CARE AND TREATMENT CASES

During the review period, the Quality Assurance Bureau worked on behalf of all types of persons served by the Mental Hygiene system — the very young and the geriatric patient; the long-term inpatient and the consumer of only clinic services; the residents of ICFs, community residences, RTFs, family care, supportive apartments and persons living at home. As diverse as the persons served were the problems solved and the allegations investigated. Poor medical care, misuse of restraint and seclusion, premature and inadequately planned discharges, ineffective protection of personal property and money, and failure to protect vulnerable residents from the maladaptive behaviors of fellow residents were among the most common. In many cases, as will be evident in the examples below, additional and sometimes more serious problems were uncovered.

❑ The mother of an individual living in an intermediate care facility complained that her daughter missed twenty-two days of day treatment programming and was in danger of being discharged from the program. Many of these absences reportedly occurred because her daughter did not have an adequate supply of clothing.

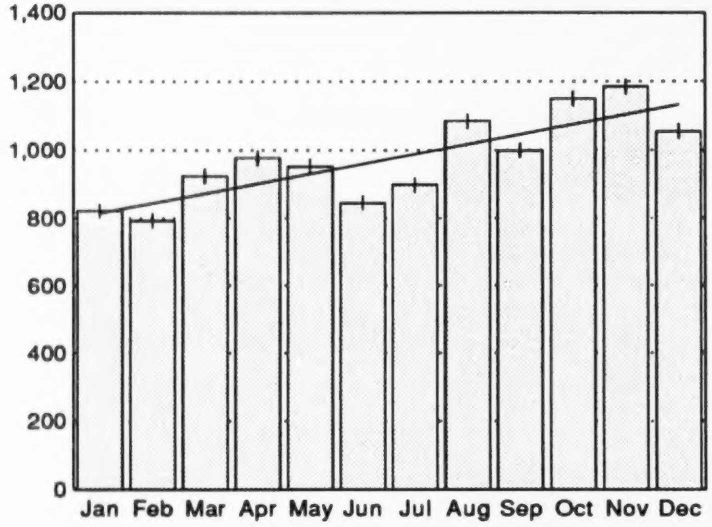
A site visit to the facility revealed that the child had excessive absences from school, there was no plan to address her behavioral needs, and incident reports were not completed on several incidents in which she sustained minor injuries.

The Commission investigation found that the child's mother insisted on doing her daughter's laundry at home, and problems reportedly occurred when the dirty clothing was not picked up or returned in a timely manner. For a five month period, the child had missed school, in total, fifty-two times. Thirteen were related to clothing, thirty were medically based, eight involved transportation issues, and one was related to an appointment for a haircut. In addition, on three of the days that the child was sick, she would have been unable to attend programming because she did not have clothing.

In response, the facility purchased clothing for the child to ensure that she had an adequate supply. Furthermore, her behavior was evalu-

800 Number Calls for Assistance

The Commission maintains a statewide toll-free number for calls from patients/residents of mental hygiene facilities and programs, their families, and other concerned advocates.



ated by the Psychology Department and staff were retrained on incident reporting procedures.

☐ At a mother's request, the Commission has been reviewing a child's care at a New York City developmental center since 1989. When we first became involved, he had a large bleeding wound on the sacral region of his back that would not heal because he scratched and rubbed the area against his chair. Our review at the time found that unit staff were not carefully monitoring his medical condition and did not have a program to address his self-injurious behaviors. Plans developed to more aggressively address the resident's medical and behavioral problems were never fully implemented after he was hospitalized for anemia.

After release to the developmental center infirmary, we found that some time between our initial and second visits, his sacral wound worsened to a Stage II ulcer, he lost twenty pounds and was reported to be in an "emaciated" state. Despite the seriousness of his medical condition, the infirmary physician had not ordered dietary supplements and staff failed to provide prescribed ulcer medication. Also, staff were still not charting the status of his ulcer, nor were they recording diaper checks, and had not implemented the program for self-injurious behaviors; all of which had been promised following our initial review.

Subsequent visits and bi-monthly reports from the facility Quality Assurance nurse revealed improvements in some areas and regressions in others. The resident's weight increased significantly following use of nutritional supplements. Also, in response to our repeated urgings, the administration developed an ulcer flow chart. However, staff did not always accurately record the progress of the ulcer, nor consistently document their observations on the flow chart. Additionally, staff did not keep a close watch on the young man or actively engage him in activities as stipulated in the behavior program devised with the help of OMRDD consultants. This laxness in supervision in 1990 and early 1991 resulted in episodes of intense scratching, during which the resident aggravated his sacral ulcer and developed new ulcers on this nose, neck and chin.

In a November 1991 letter from the Quality Assurance nurse, the Commission was informed that the lesions on the resident's chin and sacral region had improved considerably. Commission monitoring continues as the resident's weight, although now stable, is still 13 pounds below ideal body weight.

> The licensing agency was aware of these conditions and permitted continued operation, while it unsuccessfully tried to work with the family. Review by the Commission helped initiate the closure of this home and the relocation of the children to safer residences.

☐ The sister of a former patient of a psychiatric center alleged that the facility failed to provide routine preventive health care and her sister developed cancer. The Commission's investigation revealed no deficiencies in the care provided by the psychiatric center but significant problems in the medical care monitoring done by a voluntary agency community residence in which she lived. There, staff documented that the woman had a follow-up appointment after a coloscopy with negative results, but further follow-up ceased. In fact, the appointment had never taken place and her dysplasia went untreated. She developed invasive carcinoma and died within a year.

The poor medical monitoring afforded by the community residence prompted the Commission to review the operations of several of its OMH and OMRDD-certified programs. This review is on-going and has uncovered serious deficiencies in the quality of life of persons in the OMH certified programs. Additionally, the two primary providers of medical care were referred to the Health Department for failing to provide the woman appropriate care.

☐ The Commission learned through a series of allegations of abuse/neglect that three young mentally retarded, severely physically handicapped children had lived for three years in a fly-infested family care home where domestic animals ate from piles of unwashed dishware. The children were unable to use adaptive equipment because of the cluttered environs, which in some cases constituted fire code violations.

The licensing agency was aware of these conditions and permitted continued operation, while it unsuccessfully tried to work with the family. Review by the Commission helped initiate the closure of this home and the relocation of the children to safer residences.

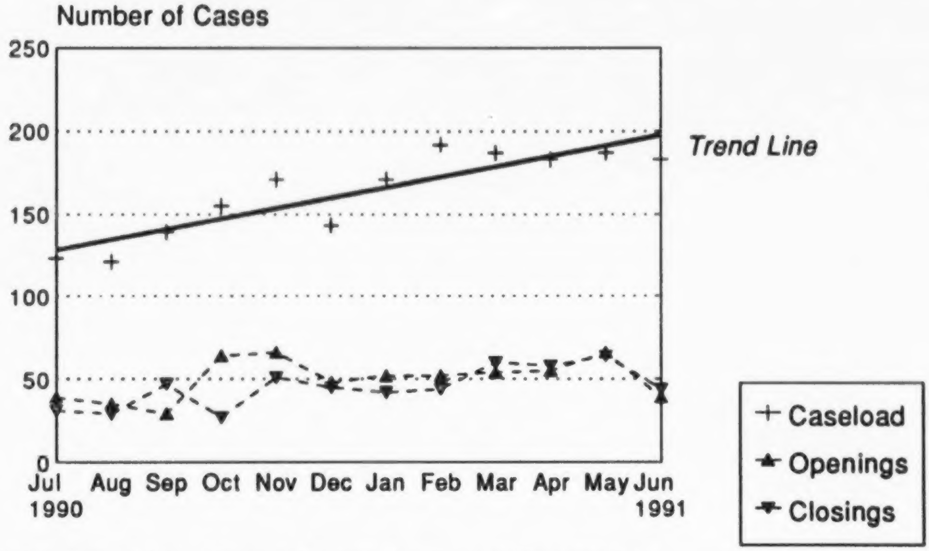
☐ Multiple complaints were received by the Commission from the professional staff at a Long Island psychiatric center during late 1990 alleging inadequate and inappropriate discharges of New York City residents to emergency shelters in the City. The Quality Assurance Bureau conducted a review of this matter for several months and monitored the discharges until the fall of 1991.

QAB's active involvement in the case encouraged the facility to: (1) explore more appropriate placement options in the NYC/Brooklyn area; (2) more closely scrutinize patients' 72-hour requests for discharge and to invoke court action in cases where patients were not ready for discharge; and (3) more actively discuss with patients requesting discharge their options and a realistic timetable for implementing an appropriate placement.

As a result of implementing the above actions, the psychiatric center's discharge of Brooklyn patients to New York City emergency shelters has been reduced to one or fewer discharges per month.

☐ The Commission received a complaint questioning the appropriateness of a Medical Center's restraint of a 24-year-old dually-diagnosed patient. Our investigation verified that the patient was dually-diagnosed, incapable of understanding the goals of treatment and of participating in treatment planning. We found that the hospital secluded and restrained the patient on two separate occasions in violation of OMRDD regulations which state that "seclusion shall *not* be used with the mentally retarded." Further, we found that the doctor's orders did not set forth the time of expiration of the restraint as required by the Mental Hygiene Law, ordering instead that the restraint be implemented "until she gained control" and be continued "until behavior improves," and on the second occasion giving no indication when the patient was to be released. Additionally, on one occasion the patient demonstrated calm and appropriate behavior for one and one-half hours, was released to use the bathroom, and displayed appropriate behavior during this release. Yet, staff attempted to return her to seclusion, in disregard of regu-

Quality Assurance Cases



Total Number of New Cases During the Report Period: 619

latory safeguards. The patient became upset and was then restrained.

The Commission recommended that the hospital review its policies and procedures and modify them as necessary for persons with developmental disabilities, specifically as they apply to the development of treatment plans and seclusion. We further recommended that physicians, nurses and other staff be retrained on the provisions of Mental Hygiene Law 33.04 and regulations NYCRR 27.7, especially regarding the conditions for reapplication and time limits for restraint and seclusion, and that the specific staff involved in these incidents be counseled.

The Medical Center accepted the Commission's findings and recommendations, agreeing to review their policies and procedures, and develop new forms and retrain staff. Both the physician responsible for evaluating this patient and writing the orders, and the staff responsible for returning the patient to seclusion despite her calm demeanor, have been counseled.

☐ The Commission conducted a review into an anonymous complaint that the Executive Director of a voluntary agency acted inappropriately when he discovered that an employee had embezzled a significant amount of client monies. This was discovered when a resident of the agency was transferred to a developmental center and his personal allowance accounts were reviewed.

During the ensuing agency investigation, the employee in question admitted to the Executive Director that she had stolen approximately $1,000 in client funds and was willing to make repayment. In response, the Executive Director took no action, informed no one, did not complete an incident report, and did not suspend the employee from duty.

Two weeks later, the Executive Director completed an incident report and notified the Board of Directors. The next day he notified the DDSO and called the State Police. An internal audit revealed that the employee had stolen $26,776.60. The employee resigned her position and reportedly has pled guilty to one count of fourth degree grand larceny.

The Commission found that the Executive Director's response was inadequate and in violation of Mental Hygiene Law and Regulation:

(1) The Executive Director placed the agency and the residents at further financial risk when he failed to inform the Board as soon as the employee admitted to taking residents' funds and when he failed to suspend her immediately. Similarly, he exercised poor judgment in his failure to order a complete audit as soon as a problem became apparent.

(2) The Executive Director did not complete an incident report until fourteen days after the incident became known to him, in violation of 14 NYCRR 624 which requires a report be completed for such a situation within forty-eight hours of discovery.

(3) The Executive Director did not contact the State Police or OMRDD until fifteen days after the incident became known to him, in violation of Section 16.13(b) of Mental Hygiene Law which requires such notification as soon as possible and no later than three days after it has been discovered that a crime may have been committed against a client.

> During the past year the PADD program served approximately 16,000 persons with developmental disabilities.

In response to this incident, the agency took corrective measures to ensure accountability for residents' funds and acknowledged the poor judgment shown by the Executive Director in this matter, noting this as an aberration from his usually skillful handling of incidents.

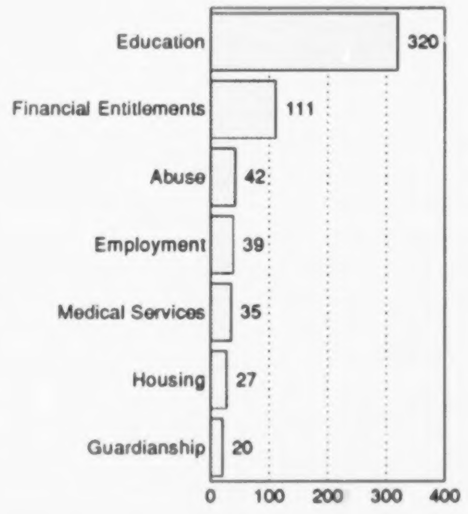
PROTECTION AND ADVOCACY FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

The Commission's Protection and Advocacy for Persons with Developmental Disabilities (PADD) Program is a federally-established and funded program which provides the Commission, through the eleven regional offices of the program, the opportunity for individualized service to persons with developmental disabilities. During the past year the

PADD program served approximately 16,000 persons with developmental disabilities. The services included legal assistance and nonlegal individual advocacy, and encompassed a variety of educational and training offerings, with special efforts to foster community integration of persons with disabilities. The following are case examples which illustrate the type of individual advocacy in which PADD staff have been engaged. Some of these cases required the use of an impartial hearing or negotiation. Others required the brokering of services in a coordinated way to bring about a change in the life of the person with a developmental disability.

Due Process Rights

☐ Having the security of your own room may for some feel like an inalienable right. The Commission's New York City-based PADD outreach office intervened on behalf of two clients who were proposed for transfer from one state-operated group home to another. The proposed move was being made to provide for more homogeneous groupings. A record review indicated that the reason for the transfer did not justify a disruption in the lives of the two gentlemen. In particular, both men had their own private rooms in the present residence and, because of their disability of autism, they did not have much interaction with the other residents. In the new residence there would be roommates and less space. With the formal objection to transfer by our New York City office, the state provider reconsidered and permitted the two gentlemen to remain in what had become their home.



Leading Case Problem Areas
PADD Program

☐ Friends for many individuals with developmental disabilities are the people who care for them on a daily basis. Neighborhood Legal Services, the PADD regional office in Buffalo, assisted a young man with deafness in his negotiations with his community residence providers. The young man wished to continue a friendship with a former employee of the residence, but was forbidden to do so by the agency, which cited a policy restricting fraternization between residents and staff. The NLS staff attorney advised the agency that such a restriction was a violation of client rights and, therefore, potential grounds for a lawsuit. The agency reconsidered and permitted the continued friendship.

Parental Custody Rights

☐ Women with developmental disabilities face discrimination when their parenting skills are called into question. The Commission's PADD program in Poughkeepsie, Mid-Hudson Legal Services (MHLS), represented a young woman with mental retardation in her fight to retain custody of her infant who has a petit mal seizure disorder. The local Child Protective Services Unit filed an abuse and neglect petition in family court alleging that the mother was incapable of caring for her child. The MHLS attorney argued that the mother needed parental skills training and requested an evaluation by the local State Developmental Disabilities Office. Upon completion of the evaluation and treatment plan, an interagency agreement was formulated between the local Child Protective Services and the State Developmental Services Office. With the help of the newly created Home and Community-Based Services (HCBS) waiver, both mother and child were placed in an enhanced family care home. The family care provider would serve as an instructor for the mom in parenting skills as well as ensuring a nurturing environment for the child. The HCBS waiver permits the use of Medicaid funds for services other than for placement in an intermediate care facility or developmental center.

SPECIAL EDUCATION RIGHTS

- The thought of having to carry a twelve-year-old child up and down six flights of stairs is monumental. In Westchester County, the PADD unit, Westchester Independent Living Center (WILC), assisted a family with their negotiations with a school district. This child had been ambulatory but became reliant on a wheelchair. The family lived in an apartment and the mother was carrying her twelve-year-old daughter piggy back style up and down six flights of stairs to meet the school bus. In the previous *Rivera v. Sobol* case brought by New York Lawyers for the Public Interest, the court ordered the State Education Department to implement a regulation providing that a porter be assigned to a school bus to carry a non-ambulatory student when there was no available ramp or elevator in the student's home. The mother was not aware of the decision and the school district believed that such a service was optional. WILC clarified the regulation for the District and the porter carry service was implemented.

- Section 310 of the New York State Education Law permits the Commissioner, after hearing arguments, to issue an order annulling the decision of a school district. The Commission's PADD program in Plattsburgh New York, North Country Legal Services (NCLS), utilized a State Education Commissioner's order to implement a 12-month program for a student with developmental disabilities. The order was necessary to circumvent the normal appeals process, since it was June and the request was for a summer program. The pendency of an appeal would have exhausted the summer months and, as was argued in the request for the order, the child would experience irreparable harm. The Commissioner ruled that the Board of Education had not applied the proper standard of "substantial regression" when it denied the 12-month program recommendation of the Committee on Special Education. Simultaneous with the Commissioner's order, the Board of Education reversed its position and let stay the decision of the CSE. This decision permitted an uninterrupted program to continue through the summer months, and thus prevent any loss of skill.

SECTION 504 OF THE REHABILITATION ACT CLAIMS

- The Federal Department of Education Office of Civil Rights has provided a receptive venue for complaints about school districts. The PADD Program in Binghamton New York, the Broome Legal Services Corporation, received a favorable federal Office of Civil Rights (OCR) decision against a school district for failing to make accommodations for a student with disabilities who was scheduled for classes on different floors of the school. In addition, the school had refused to hold dances and other social events in accessible places. This final OCR decision became necessary after the school district failed to implement the first decision under the Early Complaint Resolution mechanism of OCR. The student is now receiving a fully accessible program.

- Again, an OCR complaint was put to good use by the PADD program at the Albany Law School. At issue was the failure by a local school district to provide a resource room program for children in elementary school, despite recommendations of independent evaluators. All special education students were being referred exclusively to placement in Board of Cooperative Education (BOCES) programs. The complaint provoked a change in philosophy for the District and, in fact, the District agreed to hire a consultant special education teacher for the elementary school grades. The use of consultant teachers will provide for an even less restrictive environment than a resource room.

NEGOTIATION

- The Commission's PADD program for Nassau and Suffolk Counties, Long Island Advocates (LIA), Inc., was able to negotiate a mortgage payment low enough to permit a person with developmental disabilities and his non-disabled sibling caretaker to remain in their home. Before their mother's death, the household mortgage payments were calculated at a discounted tax rate due to the mother's senior citizen status. This discount ended subsequent to her death and the increased payment became an insurmountable burden for the adults. The LIA, Inc. attorney prevailed upon the bank, which graciously recalculated the mortgage payments by adjusting the required escrow amount used to pay the taxes.

MEDICAID RIGHTS

❑ Going to the store or a community park for the majority of us is routine, however, when confined to a stretcher, this access is almost unattainable. NYLPI won a favorable Medicaid Fair Hearing decision permitting payment for a motorized prone stretcher. The client, who has been a life-long resident in a Rehabilitation Hospital and now is in a supported apartment, had become a virtual prisoner in her home because she was unable to push herself on her manual stretcher. Also, the client's personal care attendant was unable to push the stretcher because of its height. The case had become complicated because, initially, the client was denied a fair hearing at her home and lost her first appeal. Through intervention in a class action suit entitled *Varshausky v. Perales*, in which the court granted a restraining order preventing the denial of home fair hearings, (An Administrative Law Judge conducts the hearing at the client's home), NYLPI was able to obtain an order vacating the prior hearing decision and ordering a new emergency fair hearing at which the client participated from her home by way of a speaker phone in the hearing office. The hearing produced a favorable decision. The motorized stretcher will permit the individual to have her first access to her surrounding community of Roosevelt Island.

PROTECTION AND ADVOCACY FOR PERSONS WITH MENTAL ILLNESS

The Protection and Advocacy for Persons with Mental Illness (PAMII) Program is another federally established program which has seven regional offices set up to protect rights and advocate for persons with mental illness. During the past year, the PAMII program served 2,217 individuals.

CASE EXAMPLES:

CONSUMER LOAN

North Country Legal Services, Inc. successfully represented a client who had purchased a vehicle and obtained a $7,000 loan from a local dealer. Although she informed the dealer that her only source of income was Social Security benefits and although she did not know how to drive, the dealer sold her the vehicle and assisted her in obtaining the loan.

Shortly after the purchase, the client was rehospitalized in a psychiatric unit and sought assistance to void the contract for the vehicle purchase.

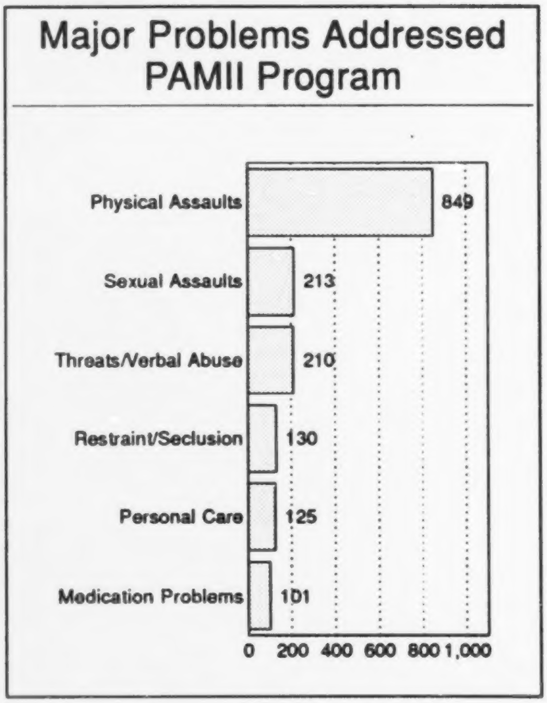
After lengthy negotiations, the loan company agreed to void all contracts, refund all money and accept the return of the vehicle without any adverse effect on the client's credit status.

MEDICAID PAYMENT FOR REHABILITATION

Legal Services of Central New York, Inc. successfully advocated on behalf of a resident at Elmira Psychiatric Center who had suffered a spinal cord injury in 1989. Their client had been accepted to an out-of-state rehabilitation facility capable of addressing his physical rehabilitation needs as well as his emotional problems. The client was denied Medicaid prior approval based on his psychiatric diagnosis, psychiatric history, and the fact that he resided in a psychiatric center.

At a fair hearing, PAMII presented testimony from the client, two members of his treatment team, and a community advocate for persons with disabilities. Also presented was documentation that the client no longer needed inpatient hospitalization for psychiatric problems and a supportive letter from a local physician who specializes in physical rehabilitation.

A favorable decision was received, directing Medicaid to provide prior approval to the client to attend the out-of-state facility. The decision noted,


Major Problems Addressed
PAMII Program

among other points, that the claim the client had a poor rehabilitation potential based on psychiatric history was not supported by his clinical record. Shortly after the decision was received, the client moved to the rehabilitation facility.

MAINTAINING A RESIDENCE

Neighborhood Legal Services, Inc. of Buffalo was successful in representing a hearing impaired client who was suspended from a community residence program and threatened with discharge. The client had been living in a group situation and was frustrated because of his desire to achieve more independence.

Through extensive negotiations with the residential program and the Office of Mental Health, the PAMII program was able to prevent the client's discharge from the residential program and to obtain a less supervised supportive apartment for him within the same program.

Since the client did want to leave the program at some time, PAMII also negotiated a discharge plan, which included an agreement by the residential program to provide for transition of the client into independent living, as well as to provide supportive case management services even after he left the residential program.

EMPLOYMENT DISCRIMINATION

Disability Advocates, Inc., a PADD office based in Albany, was successful in advocating for a client in a handicap discrimination case by a federal agency. The client was a federal employee who was placed on seasonal furlough. When he learned of the furlough, he became depressed and was briefly hospitalized.

The agency where he was employed would not recall the individual to work unless he was willing to provide extensive and probing medical and psychiatric information, something not required of individuals who have been hospitalized for medical reasons.

Disability Advocates assisted in filing a formal complaint alleging handicap discrimination with the Equal Employment Opportunity office of the federal agency. A favorable settlement was reached with the agency, and the client has returned to work in a better position than when he was originally furloughed.

CLIENT ASSISTANCE PROGRAM

The New York State Client Assistance Program (CAP) is a federal program administered by the Commission designed to help persons with disabilities secure rights, benefits, and programs available to them under the Federal Rehabilitation Act.

CAP continues a high level of commitment to the activities of the Interagency Council on Vocational and Related Services, established between the Governor's Office and the Regents and comprised of ten state agencies engaged in the delivery of vocational advocacy and related services. Through participation in this Council, CAP has focused attention on addressing the systemic issues encountered by applicants for, and recipients of, vocational rehabilitation services.

During the past year, CAP served 7,291 New Yorkers with disabilities, their advocates, and service providers. Among these were 1,106 consumers who received intensive case advocacy services. CAP secured a favorable decision in 95 percent of the cases which were advanced for a service determination. This high success rate reflects the Client Assistance Program's strong commitment to consumerism and issue resolution. The number of individuals served is the highest in the Commission's seven year history with CAP and continues to demonstrate the high demand for CAP services.

The following case examples are illustrative of the types of problems presented to CAP during the past year. (While these are actual cases, pseudonyms have been used to protect consumer confidentiality).

TRANSITION FROM SHELTERED EMPLOYMENT TO SUPPORTED EMPLOYMENT

Ms. Strand is an Office of Vocational and Educational Services for Individuals with Disabilities (VESID) consumer with a learning disability who approached CAP for assistance in identifying an alternative to her current sheltered employment placement. Ms. Strand and her parents believed the placement in the workshop setting was inappropriate and articulated what they perceived to be a lack of effort on the part of the VESID counselor to explore alternative employment options. CAP facilitated the consumer's linkage to supported employment programming, and other community-based services. The results were dramatic in that in addition to placement in a suitable supported employment placement, supported living services were also secured, enabling Ms. Strand to live more independently.

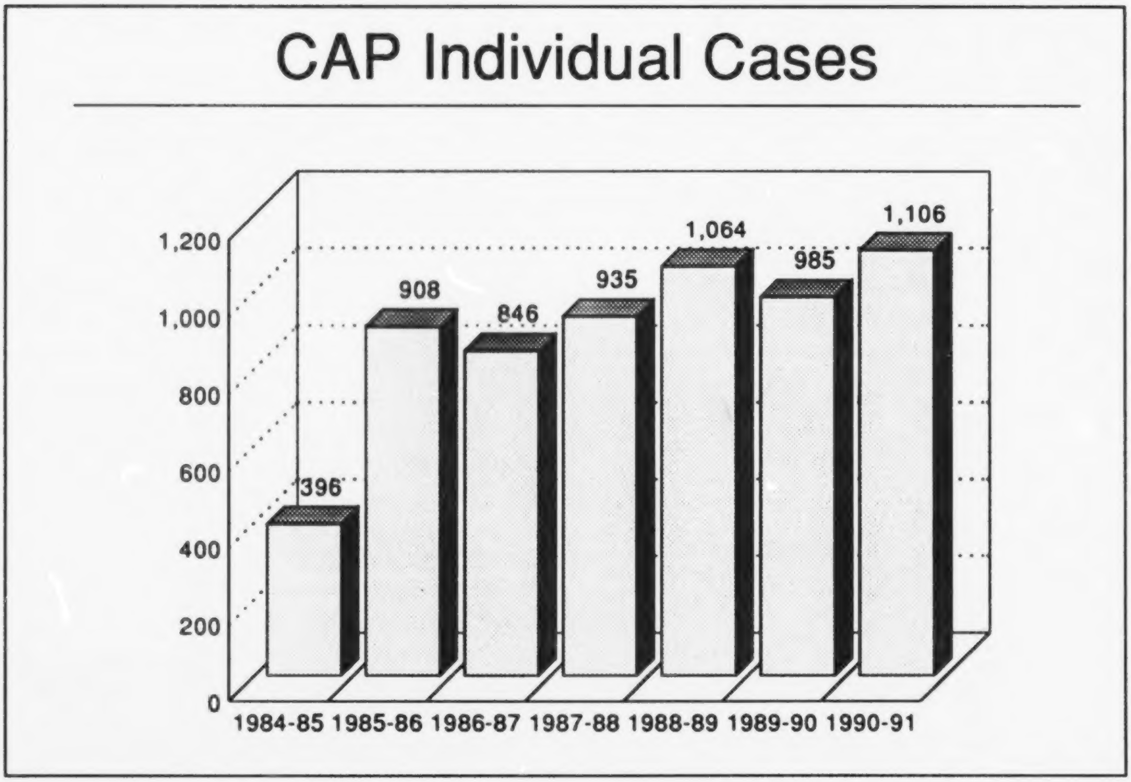
CBVH GOAL/EDUCATIONAL SERVICES

Ms. Fox is a 27-year-old Commission for the Blind and Visually Handicapped (CBVH) consumer who is legally blind and deaf with some residual hearing. She was employed at the Northeast Association for the Blind in sheltered employment when she approached CAP for assistance in securing CBVH sponsored training to prepare her for the GED exam and a high school diploma. Due to Ms. Fox's "employment status," CBVH denied assistance. CAP pointed out that the consumer's residual hearing continues to deteriorate, and the skills Ms. Fox would acquire in pursuit of a high school diploma would better position her for future rehabilitation, independent living and employment. CAP noted that sponsorship now would be likely to lessen the extent of service CBVH will be called upon to furnish in the future. CBVH agreed and sponsored Ms. Fox for GED exam training.

ADAPTIVE EQUIPMENT EVALUATION

Mr. White is a VESID consumer who is quadriplegic as a result of a spinal cord injury. He sought assistance from CAP in resolving a dispute with VESID over an evaluation undertaken to identify how he could better utilize existing computer equipment at his work site and at home. The quality of the computer evaluation was questionable in that it consisted of two conversations by phone. The VESID sponsored evaluator did not have the benefit of observing Mr. White negotiating the computer keyboard and in physically inspecting the computer equipment in question. Mr. White's primary concern centered on a delay of four months before a written summary of the evaluation was submitted to VESID.

Timeliness was a critical concern for Mr. White, in that he had hoped to utilize personal resources from his Social Security Plan for Achieving Self-Support (PASS) to purchase the recommended computer equipment. Due to the delay however, his PASS had expired and he utilized the remaining PASS funds to purchase equipment for his modified van. VESID consistently maintained that the requested services had been provided and that the evaluation was sufficient to meet Mr. White's needs, and his case was subsequently closed. CAP made every effort to negotiate the re-opening of Mr. White's case and to negotiate VESID support for an adequate computer and work site evaluation to no avail. CAP then advised Mr. White to request an administrative review. CAP representation was provided at the review,


CAP Individual Cases

where the District Office Manager agreed to re-open Mr. White's case and to refer him to an alternative computer and work site evaluation.

CBVH LIMITED TRAINING OPTION

Ms. Ray is a 40-year-old CBVH consumer who is legally blind. Ms. Ray solicited CAP assistance, frustrated by the limited training options presented by her CBVH counselor. CBVH had recommended placement in a sheltered workshop, despite Ms. Ray's educational background, which included some college and a substantial work history. CBVH had determined that Ms. Ray's emotional problems prevented her from participating in anything more competitive. While Ms. Ray did not have clearly marketable skills, there had been little action on the part of CBVH to compensate for her emotional difficulties, and to identify more creative training or employment options. The CAP advocate undertook an extensive search and identified a supported employment program which would provide an appropriate placement. CAP then successfully advocated for CBVH sponsorship. An extended evaluation at the agency's workshop was prescribed as a prerequisite to supported employment. It was during the extended evaluation that Ms. Ray sensed little progress and became trapped in feelings of depression and worthlessness. The "Catch 22" Ms. Ray faced is that, due to the lack of support and lack of movement toward a viable goal, she deteriorated in the evaluation phase and was assessed as not ready for supported employment. As a result, Ms. Ray left the program, found a volunteer position and remains there today without the benefit of CBVH support. She also remains very apprehensive about requesting services in the future. Ms. Ray represents just one of many consumers who fall out of the vocational rehabilitation service delivery system.

VESID CASE CLOSURE

Mr. Burgman is a 23-year-old VESID consumer who has end stage renal disease. He approached CAP because his VESID counselor had informed him by phone that she was closing the case on the grounds that Mr. Burgman was too disabled to work. Upon investigation, CAP found Mr. Burgman to have average intelligence and some physical limitations, but could not see the justification for closing his case. CAP initiated a meeting with Mr. Burgman and the VESID counselor and requested the case be re-opened. Additionally, since an evaluation had recommended clerical training in a clean environment, CAP suggested that Mr. Burgman visit three facilities to evaluate which would be most suitable to meet his training needs. VESID agreed and arranged site visits. After several visits, Mr. Burgman chose North Shore Vocational Rehabilitation Center, which is connected with North Shore Hospital as the most appropriate training site. He was able to coordinate his dialysis treatment so that they would not interfere with his training. Mr. Burgman is delighted with the outcome of his rehabilitation plan and is progressing well on the training site.

VESID HOME MODIFICATIONS

Ms. Easton is a VESID consumer who is paraplegic and uses a wheel chair as a result of a spinal cord injury. Ms. Easton is pursuing a career in the secretarial field and requested home modification services from VESID. Nearly two years had passed before the services were ultimately provided. Ms. Easton was so frustrated by the process to secure the installation of a wheelchair ramp and bathroom modifications that upon the third assessment by VESID to develop a design plan, she insisted that the VESID representatives leave her home.

Several factors contributed to the home modification turning into a harrowing experience. The individuals dispatched by VESID to undertake the initial home assessment clearly had lacked adequate design and construction skills. The resulting "design plans" were consistently vague, providing little direction to bidding contractors, and little hope for effective oversight. According to VESID, Ms. Easton's input into the changes to take place to her home was not required, and her approval of the proposed renovation was not insured until CAP was called to assist with the case. One overriding barrier was VESID's policy limiting home modifications to $7500 which, in Ms. Easton's case, was an unrealistic cap on expenditures. The CAP advocate had extensive contact with the local VESID office in an effort to resolve the case, and finally communicated with VESID's Central Office. Ultimately, CAP was successful in advocating for an objective architect to undertake a final assessment. VESID agreed to secure an architect who made a realistic appraisal of the home modification requirements, involved Ms. Easton in the assessment process, and developed specifications, to be utilized for the sixth round of bidding. Nearly two years after the initial request for services, Ms. Easton's home modifications were completed.

LEGAL ADVOCACY

The power to litigate has been the tool of last resort in federal advocacy programs administered by the Commission. Over the years, litigation has been used successfully in reaffirming and enforcing constitutional rights for individuals with disabilities. The following are examples of legal actions pursued during the past year.

PADD LEGAL ACTIONS:

HOUSING RIGHTS

125 West 96th Street Residents Association v. 125 West 96th Street Owners Corp. No. 4641/91, Supreme Court, New York County

The efforts to depopulate large institutions are dependent on a full range of community housing options. This case blocked the attempt by owners of cooperative apartments to use the zoning laws and the building's proprietary leases to prevent apartments from being used for supported living for persons with developmental disabilities. The Commission's PADD Program Legal Support Unit for New York City, New York Lawyers for the Public Interest (NYLPI) successfully opposed an attempt by apartment owners and residents on Manhattan's Upper West Side to prevent an agency for persons with disabilities from opening five supportive apartments in the building. Project L.I.F.E. had negotiated contracts of sale and entered into pre-closing occupancy leases for five apartments in a cooperative. The Project L.I.F.E. participants would live independently in the apartments with Project L.I.F.E. providing approximately 5-10 hours of supportive services such as assistance in planning meals, budgeting, housekeeping, etc. In order to ensure its funding for the apartments from the New York State Office of Mental Retardation and Developmental Disabilities, Project L.I.F.E. needed to close on the apartments and take occupancy by March 31, 1991.

Two tenant-shareholders and an organization of residents of 125 West 96th Street obtained an *ex parte* temporary restraining order enjoining Project L.I.F.E. from occupying and purchasing the apartments. The residents contended that the apartments were being used as "a social service agency" rather than as residences, in violation of the zoning law, the certificate of occupancy, and the proprietary lease. They also alleged that residency by the Project L.I.F.E. participants "places all of the tenants at the premises at risk." In addition, the residents claimed that "there will be a severe diminution in the value of the shares and shareholders will be subject to significant economic losses."

In less than a week's time, NYLPI put together a brief and affidavits stressing the legality of Project L.I.F.E.'s purchase and occupancy of the apartments and pointed to violations of the recently-enacted federal Fair Housing Act should the residents' position prevail.

On the return date for the preliminary injunction, the trial judge immediately vacated the restraining order and stated that the order should never have been signed in the first place. He strongly hinted that his decision to vacate the restraining order indicated how he would ultimately rule in the case. The residents then agreed to "settle" the matter and dismiss their complaint. As a result of NYLPI's assistance, the Project L.I.F.E. participants were able to move in prior to the March 31, 1991 deadline.

RIGHTS IN INSTITUTIONS

Lichtman v. Blom, 89 Civ. 5643, Southern District of New York

NYLPI wrote an *amicus curiae* brief in this important case involving confidentiality protections for whistleblowers in nursing homes. Many individuals with developmental disabilities live in nursing homes and intermediate care facilities. This case was therefore of significant importance to people with developmental disabilities.

In this case, the nursing home sought disclosure of the names of nursing home employees who had complained of patient neglect to an advocacy group, Friends and Relatives of the Institutionalized Aged (FRIA). The district court had initially ordered the advocacy group to disclose their names to the nursing home's attorneys, holding that the employees were not protected under N.Y. Health Law § 2803-d(6)(e) because they had made their reports to FRIA. The court held that the statute only protected disclosure to the Department of Health. Subsequently, the employees moved to intervene to preclude disclosure of their identities.

NYLPI submitted a brief on behalf of *amici curiae* New York City Chapter of the Gray Panthers, New York Statewide Senior Action Council, Nursing Home Community Coalition of

New York State, and Public Health Association of New York City, which demonstrated that nursing home abuse and neglect is widespread and widely underreported, and argued that confidentiality was essential because employees justifiably fear retaliation. NYLPI explained that restricting disclosure to attorneys would not lessen the fears of the employees. NYLPI argued that the First Amendment protected the confidentiality of nursing home whistleblowers.

Judge Keenan granted the employees' motion and held that FRIA could not be required to disclose their identities. The court found that the employees were in fact protected by the statute, since they had first reported the patient neglect to the Department of Health, which advised them to report the patient neglect also to FRIA. Although the court did not reach the First amendment issue, the decision was a substantial victory since it protected the identities of the whistleblowers.

MEDICAID RIGHTS

Dobson v. Axelrod and Perales (Appellate Division, Fourth Department)

The interpretation of medical necessity for durable medical equipment became the issue in this action. This was an appeal brought by the Commission's PADD legal support unit in Buffalo, Neighborhood Legal Services (NLS), following an adverse fair hearing decision which sustained the denial of Medicaid funding for a wheelchair. At issue was a request for a second lightweight wheelchair for an individual already in possession of a motorized chair.

In only the second recorded New York State decision on Medicaid funding for a wheelchair, the Court reversed the fair hearing decision and awarded the client the second lightweight customized wheelchair. It was the Court's opinion that, without the second chair, the client would not have access to many medical, vocational and recreational activities.

Hines v. Perales

The use of Medicaid has become an important tool in preventing institutionalization for children with severe medical needs. The Commission's PADD program for the northern part of the state, North Country Legal Services (NCLS), is representing a named plaintiff in this state-wide class action filed in the Western District of New York. The lawsuit challenges a recent New York State Legislative repeal of the exemption from income given for mandatory payroll deductions when calculating Medicaid eligibility.

The plaintiff is a three-year-old boy who suffers from pulmonary dysplasia, a seizure disorder and various other medical conditions. The child was hospitalized for the first year of his life and, since returning home, he requires 24 hour nursing care and a respirator. Although both parents are employed, their medical insurance does not cover the cost of nursing care or the durable medical equipment.

The child is Medicaid-eligible as a disabled child but subject to a monthly spend-down of parental income. Since repeal by the Legislature, the required monthly medical spend-down has increased from $75 to $750 per month.

The class action alleges that the change in State Social Services Law eliminating the exemption given for the mandatory payroll deductions violates the Federal Social Security Act and the Constitution.

Plaintiff's motion for a preliminary injunction enjoining implementation of the statute was denied. The case is now being appealed to the Second Circuit.

The child in question may be eligible for a Katie Beckett waiver, which allows for Medicaid eligibility for a child who has been in a hospital for 30 days or longer by waiving parental income eligibility if it can be proven that remaining in the home would be cheaper than placement in a facility. However, the issue remains significant for many other children similarly situated who may not have such an eligibility for waiver. The waiver is granted by the Federal Government for a limited number of individuals, leaving many more to meet the medical expense spend-down formula.

McMahon V. Perales et al. (U.S. District Court WDNY)

The package of Supplemental Security Income (SSI) and Medicaid benefits is crucial for survival for persons with disabilities. This lawsuit is being brought by Buffalo's Neighborhood Legal Services (NLS) against the New York State and Erie County Departments of Social Services to challenge their failure to implement the provisions of 42 USC §138c(c). This provision requires that individuals who, after July 1, 1987 lose their entitlements to SSI as a result of the receipt or an increase in the monthly amount of their Social Security Disabled Adult Child's benefits, shall continue to receive Medicaid automatically as if they were still SSI recipients. This statewide class action claims that the state has not implemented policies and procedures to ensure that those individuals who are eligible for continued Medicaid are properly certified as eligible.

The typical class member is an adult with mental retardation who receives Social Security benefits on the earnings record of a parent when that parent dies, retires or becomes disabled. It has become a pattern in New York State that, once the persons loses SSI, so too goes the Medicaid. The loss of Medicaid can result in a significant change in the life of an individual with developmental disabilities. For without such a benefit, residential care and day programming would be placed in jeopardy.

SECTION 504 OF THE REHABILITATION ACT CLAIMS

Hackett v. Board of Education of the Holland Central School District

Equal access for a student with a disability, who was otherwise qualified, became the issue for this Federal lawsuit. In an action reminiscent of a previous case brought by this office in *Doe v. Greece Central School District*, Neighborhood Legal Services, challenged the Holland Central School District's actions in refusing to permit participation in regular physical education classes for a pupil who is blind in one eye. In the *Doe* case, the pupil had requested to play on the football team.

However, the Holland School District's actions had a more deleterious affect since the pupil's lack of participation in physical education caused a failure in the course and thus denial of graduation. NLS alleged violations under Section 504 of the Rehabilitation Act of 1973 which prohibits discrimination against a handicapped individual who may be otherwise qualified. In addition, a claim was made under the equal protection and due process clauses of the Constitution.

In a settlement agreement signed by both parties, the Holland School District agreed to grant the physical education credit and high school diploma in addition to $500 in damages.

Neale v. Community Hospital of Schoharie County, Inc.

Section 504 of the Rehabilitation Act of 1973, as the precursor to the Americans with Disabilities Act, offers employment protection for persons with disabilities. The Commission's Protection and Advocacy Program for Persons with Developmental Disabilities Legal Service Office, the Albany Law School Disabilities Law Clinic, is pursuing this reasonable accommodation and employment discrimination case. At issue is Ms. Neale's allegation that the hospital did not grant a reasonable accommodation to her disability of epilepsy when they transferred her to a high stress telephone answering job in the billing department. Further, she alleges that the pitch of a female voice on the other end of the phone line caused a seizure, thereby leading to termination from her hospital employment.

The Law School received a favorable preliminary decision from the U. S. District Court for the Northern District which may bode well for a future trial victory. Federal Judge Munson ruled against the Hospital's motion to dismiss on the claim that private employer recipients of federal financial assistance have no obligation to modify or accommodate job requirements for otherwise qualified handicapped individuals. Judge Munson stated that Section 504 of the Rehabilitation Act of 1973, 29 USC Section 794 states that there is an affirmative obligation to make reasonable accommodation for a handicapped employee. Quoting *Marsh v. Arline*, Munson went on to state, "Although they are not required to find another job for an employee who is not qualified for the job he or she was doing, they cannot deny an employee alternative employment opportunities reasonably available under the employer's past existing policies." Further, 45 CFR Section 84.12(b)(2) indicates that reasonable accommodation may include job restructuring.

However, in activity not related to the court case, Ms. Neale's neurologist had been studying the "voice triggers" to Ms. Neale's seizures and determined the validity of Ms. Neale's claim that *Entertainment Tonight* host Mary Hart's voice could cause a seizure. The neurologist published his findings in a letter to the *New England Journal of Medicine* which was picked up by the wire services.

The resulting publicity led national talk show hosts to satirize Mary Hart's elocution as being a questionable talent. Ms. Hart was so moved by the escalation of the issue that she made a public apology for any hurt that may have come to Ms. Neale. In order to confront the rash of misinformation, Ms. Neale came from behind her veil of anonymity and requested a news conference before the Capital District press.

Ms. Neale's appearance with her ALS attorneys helped to set the record straight and put the lawsuit back "on track." The Albany *Times Union* followed the press conference with a very sensitive series of articles on epilepsy and outlined the "real" issues of employment discrimination. The *American Bar Association Journal* in its October issue covered the salient issues of the case as well. With the publicity put aside, preparations continue for a 1992 trial date.

Pellechi v. Longwood School District

Sports participation for people with disabilities has become another avenue to full inclusion. The Commission's PADD office for Nassau and Suffolk Counties, Long Island Advocates, (LIA) Inc., represented a young teenager with deafness who wished to participate in interscholastic sports. The school physician refused to grant the young lady a medical clearance and the District advised that, pursuant to Education Law 3208-a, a court order needed to be obtained in order to overrule the doctor's evaluation and relieve the school of any subsequent liability. Unlike the case reported by NLS, this school district invited court action.

The LIA, Inc. attorney researched the applicable laws and went about securing an appropriate court order compelling the school to allow interscholastic sports participation. Ironically, no federal law violations needed to be claimed; rather, the order amounted to an exemption from the Education Law. The applicability of such a state law may be held in question with the effectuation of the Americans with Disabilities Act in January and July of 1992.

SPECIAL EDUCATION RIGHTS

Gary M. and Ruth M. on Behalf of Emily M. v. Thomas Sobol and South Lewis Central District
89-CV-1061 (WDNY)

There are times when full exhaustion of administrative remedies may be circumvented in pursuit of a Federal claim. This action has been brought by the PADD program in Syracuse, Legal Services of Central New York LSCNY. At issue is a parent's desire to have her child, who is mentally retarded, placed into a regular education classroom. The school district had recommended an Option IV class (more restrictive, self-contained class) which the mother appealed to an Impartial Hearing Officer. The Hearing Officer ruled that the School District should consider instead an Option II class, which would be less restrictive but still in a segregated environment.

The lawsuit is a civil action brought under the federal Individuals with Disability Education Act (formerly E.H.C.A.) and makes a federal claim of entitlement to a full inclusion program. Chief Federal Judge Neal P. McCurn for the Northern District of New York is considering the motions of both parties for summary judgement. Oral arguments have been presented and a decision is anticipated in 1992.

Denise T. v. Shalmont School District

Although inclusion of children with disabilities into the regular education system is the spirit of the federal Individuals with Disabilities Education Act, heretofore New York State has been tardy in accomplishing this goal. Although this action never needed court intervention, the administrative review and ultimate State Review Officer decision presented a landmark precedent for the full inclusion of children with disabilities into a regular education classroom. At issue was the recommendation of three independent evaluators that Denise would benefit from full mainstreaming with consultant teacher services. The school district was reluctant to provide such inclusion because of concerns about the regular education teacher's reactions to integration. In addition, the teacher's union had taken a strong position against the concept of full inclusion for special education students.

After a six day Impartial Hearing, the PADD program in Poughkeepsie, Mid-Hudson Legal Services (MHLS), prevailed and received a decision specifying that Denise was to start her regular education placement by a specific date. Denise's mother planned to send her daughter to school on that date despite some indication that the District would appeal the Hearing Officer's decision. The publicity attendant to Denise's planned arrival at the schoolhouse door did heighten the community's awareness of the inclusion issue. The school district decided to appeal, rather than to implement the Hearing Officer's recommendation, and denied the child entry to the regular classroom.

After hearing positions from both sides, the State Review Officer sustained the Hearing Officer's decision and ordered mainstreaming with appropriate support services. In the most expansive discourse on the merits of mainstreaming ever presented in a decision, the State Review Officer clearly enunciated that a child may not be considered for a segregated environment until it has been shown that placement in regular education with supports will not meet the goals of the student's Individual Education Plan (IEP). Further, the Review Officer expounded on the social benefits derived to both non-handicapped and handicapped students in an inclusive educational environment.

This decision has been used to buttress many subsequent legal arguments in favor of inclusion. In fact, the State Education Department will be incorporating the language of this decision into amendments to the Part 200 regulations which govern the delivery of special education services.

PAMII LEGAL ACTIONS

LIMITS ON CONSERVATORSHIPS

Disability Advocates, Inc. filed an *amicus curiae* brief on behalf of thirteen organizations, and the New York Court of Appeals decided that the conservatorship statute, Mental Hygiene Law Article 77, does not permit a conservator or a court to involuntarily commit the conservatee to a nursing home.

The individual plaintiff in this case, *Grinker v. Rose*, was a woman for whom the Commissioner of Social Services in New York City was the conservator. It was the opinion of social services officials that this individual was unable to maintain her life independently, so a nursing home placement was ordered and supported by a lower court.

The decision in this case is very important because it held that without proof of incompetence in a committeeship proceeding, the conservatee's personal liberty cannot be significantly restrained. The power of a court and a conservator had often been assumed to include control over personal decision-making. The unanimous court strongly reiterated the heavy burden on one seeking to impose a conservatorship.

REGULATION OF RESEARCH ON HUMANS

New York Lawyers for the Public Interest, Inc. and Disability Advocates, Inc. have joined with Mental Hygiene Legal Service for the First Department in a lawsuit *T.D. v. Surles* in Supreme Court, City of New York. This lawsuit challenges certain portions of new regulations from the NYS Office of Mental Health which authorize research projects on human subjects who may not be capable of consenting. The lawsuit focuses on physically intrusive experiments (such as drugs, ECT, and surgery) involving persons who are deemed incapable of making a decision as to whether to participate in a research project. The suit asserts that, if an individual is incapable of giving consent, no research can be performed using that individual. The suit also challenges the use of minors in research without parental consent or in situations in which the treatment is not in the minor's best interest.

This case will significantly affect the manner in which research is conducted and the risks to which patients may be subjected. The case also raises important legal questions about the due process rights of incompetent patients who do not object to treatment but are unable to give informed consent.

The parties in this lawsuit have unsuccessfully attempted to negotiate a settlement and discovery is continuing.

CONFIDENTIALITY

Disability Advocates, Inc. has also filed a suit against a hospital for damages related to the hospital's alleged release of confidential information about a patient without her consent and contrary to her explicit instructions. The lawsuit, *E.K. v. New York Hospital-Cornell Medical Center*, is being vigorously opposed on jurisdictional grounds, with the hospital's attorney alleging that the failure to name the plaintiff deprives the court of jurisdiction. The hospital's effort to compel the plaintiff to publicly identify herself is extremely ironic since it is the hospital's insensitivity regarding privacy issues which led to the lawsuit. At the time of this report, Disability Advocates is awaiting a decision on the defendant's motion to dismiss.

ERRONEOUS HOSPITALIZATION

Touro College, Jacob Fuchsberg Law Center has filed a federal civil rights action which seeks damages because of the confinement of the plaintiff pursuant to Criminal Procedure Law, Section 730.40. This section of the Criminal Procedure Law had previously been declared unconstitutional in *Ritter v. Surles*, but the NYS Office of Mental Health had neither appealed the decision nor implemented any changes to accommodate it.

Because of the failure of the Office of Mental Health to enforce the *Ritter* decision, the plaintiff in the current action, *Arnold v. Surles*, was erroneously hospitalized.

DISCHARGE OF A CONSERVATOR

Buffalo's Neighborhood Legal Services, Inc. continues its work on *In the Matter of the Application of R.C. for the Removal of a Conservator*, in New York State Supreme Court. The conservator who had been appointed to represent the interests of R.C. had not been providing for his needs for many years.

An order settling the case was obtained which had numerous provisions which were favorable to the plaintiff, including discharge of the conservator once accountings were filed. The conservator, however, failed to comply with providing the required accountings and Neighborhood Legal Services has filed a motion for contempt against him. An order has now been granted holding the conservator in contempt of court and ordering a term of imprisonment and a fine if accountings are not provided within a 60 day period.

FAMILY VISITATION

Neighborhood Legal Services of Central New York, Inc. represented a mother who resides in a community residence in obtaining reasonable visitation with her children in *R.A. v. C.A.* in Family Court, Otsego County. Despite the existence of a court order for "liberal visitation" between mother and children, the respondent in the case would not allow the children to visit with their mother outside of his presence because of her diagnosis of mental illness and because of her residing in a supervised community residence.

Following the trial, the judge found in favor of the plaintiff. The respondent was ordered to transport the children to their mother's residence for an unsupervised eight-hour visitation one day per week.

CHILD CUSTODY

Legal Services of Central New York, Inc. also intervened in a situation in which a young woman who had just given birth had her child taken into the custody of the Department of Social Services. This case, *In re D.M.*, in Family Court, Onondaga County, deals with a child welfare caseworker who did not advise this woman of her right to an attorney or to the presence of her custodial parent during an interview which resulted in the young woman signing a consent for temporary foster care placement.

At the court hearing, the PAMII attorney demanded that the consent be declared invalid, since the client was unaware of her due process rights, and that the child be returned. The Department of Social Services filed a neglect petition against the young woman alleging that her psychiatric diagnosis was grounds to render her unable to provide care for her newborn child. The parties then agreed to a temporary order returning the child to its mother, with supervision by the social services agency.

CAP LEGAL ACTIONS

McGuire v. Switzer

The New York City CAP Legal Support Unit, New York Lawyers for The Public Interest (NYLPI), settled a long standing case of *McGuire v. Switzer*, in which the plaintiff was an OVR consumer whose approved vocational goal was a career in law. During his undergraduate education, however, OVR adopted caps on reimbursement for tuition and maintenance and the plaintiff had to assume significant debt to complete law school. In January 1986, Phillips, Nizer, Benjamin, Kirk, and Ballot, a NYLPI participating law firm commenced the lawsuit asserting the caps: denied McGuire equal protection by compromising his individualized rehabilitation plan in violation of the Rehabilitation Act; treated McGuire disparately from other similarly situated individuals; and discriminated on the basis of his disability. Following protracted negotiations, McGuire and VESID entered into a Stipulation of Settlement providing McGuire with $16,000 to be utilized toward offsetting a portion of the costs McGuire incurred in connection with his attendance at law school.

Pokobla v. Ryan

New York Lawyers for the Public Interest filed an Article 78 complaint in State Supreme Court challenging a policy of the Commission for the Blind and Visually Handicapped (CBVH). Ms. Pokobla is a CBVH consumer seeking sponsorship for law school following paralegal training. While performing as a paralegal, it was apparent that Ms. Pokobla had skills and abilities which far exceeded her level of employment. The case addresses an important "upgrading" issue in the delivery of vocational services. The Rehabilitation Act of 1973, as amended, calls for services to be provided consistent with an "individual's ability." This requirement of the Act, however, is narrowly interpreted in practice by CBVH and VESID, both of which consistently close cases upon employment of any kind, often when employment is clearly entry level, and when the consumer's abilities have been demonstrated to exceed entry level employment.

This case is likely to be of considerable significance to others who have received rehabilitation services and been placed in entry level jobs, as there is little existing case law addressing this critical issue.

Moore v. Ryan

New York Lawyers for the Public Interest filed an Article 78 complaint in State court against the Commission for the Blind and Visually Handicapped in another "upgrading" case. Mr. Moore is a CBVH consumer who is blind and is seeking CBVH sponsorship for law school. Mr. Moore, who has a bachelors degree in social work, came to New York State from Kentucky where he had been employed as a social worker. Mr. Moore enrolled and was accepted at Fordham Law School following a year-long unsuccessful job search for employment in New York as a social worker. In New York, unlike Kentucky, a Master's Degree is generally required for employment in the social work field. Mr. Moore attempted to assume all of his law school expenses with personal resources for his first year of studies, but when he no longer could fund his law school education, he approached CBVH for sponsorship and was denied.

Again, New York Lawyers for the Public Interest will be relying on Mr. Moore's protection under the Rehabilitation Act of 1973, as amended, calling for services to be provided consistent with an "individual's ability." A decision is pending.

CAP FAIR HEARINGS:

VESID FAIR HEARING/TUITION ASSISTANCE POLICY

The Western New York CAP Legal Unit, Neighborhood Legal Services Inc., successfully represented three consumers at fair hearings challenging VESID's tuition assistance policy. VESID's annual tuition assistance cap of $1650 falls short of annual SUNY tuition expenses totaling $2150. These consumers had no access to alternative financial aid or loans and, hence, the VESID's funding cap had the effect of denying the option of college participation. In presenting the case, CAP relied on a Rehabilitation Services Administration directive to VESID which explicitly indicated that caps on services could not have the effect of denying a consumer vocational rehabilitation. With the lack of alternative resources available to these consumers, CAP successfully demonstrated that the result in these cases would be to deny vocational rehabilitation services. In the fair hearing officer's recommendation, VESID was directed to assume the total cost of tuition.

VESID FAIR HEARING/ SELF-EMPLOYMENT

The Long Island CAP Legal Unit, Long Island Advocacy Center Inc., represented a VESID consumer at a fair hearing challenging VESID's denial to sponsor him in self-employment as a music composer. The case demonstrates the often extremely high standard imposed on consumers who wish to pursue self-employment. The case also represents the often grueling and litigious nature of the fair hearing process for consumers. Mr. Manning is a VESID consumer who had experienced a head injury. Prior to incurring his disability, Mr. Manning had an illustrious career as a music composer, having served as Burt Bacharach's music director and had composed music for a number of major motion pictures. Mr. Manning had proposed a plan for self-employment which would allow him to continue to compose music from his home. VESID denied the plan and refused to purchase the required adaptive technology identified in the plan, namely a personal computer and appropriate software.

CAP demonstrated that an array of diagnostic testing had confirmed that Mr. Manning had the ability to compose music and, in addition, presented documentation from a number of notable performers and management personnel in the music industry attesting to the viability of his occupational objective. The VESID attorney was, in CAP's opinion, extremely confrontational in his approach and exercised excessively intimidating tactics in his examination of Mr. Manning. While the hearing officer recommendation supported VESID's initial determination, the VESID Commissioner overruled the hearing officer and granted Mr. Manning support for his self-employment plan.

CBVH ADMINISTRATIVE REVIEW/ COLLEGE ROOM AND BOARD

The Brooklyn area CAP Outreach Unit, Brooklyn Center for Independent Living, represented a 38-year-old CBVH consumer attending New York University at an administrative review, challenging CBVH's denial to defray room and board expenses associated with his attendance at the University. CBVH allows for room and board expenditures to be covered on campus when the home environment is not conducive for academic study despite proximity to the campus. In this consumer's case, six people lived in a two bedroom apartment which clearly demonstrated a non-conducive environment to academic study. The necessity for the consumer to reside on campus was further indicated due to the burdensome nature of the commute to the campus which for a one way trip included over an hour of bus travel. While CAP was unsuccessful at the administrative review level, Central Office CBVH was contacted following a request for a fair hearing and negotiations resulted in CBVH agreeing to cover ongoing room and board expenses thus averting a fair hearing.

VESID FAIR HEARING/ COLLEGE SPONSORSHIP

The CAP Central New York Legal Unit, Legal Aid Society of Mid-New York, successfully represented a 46-year-old VESID consumer at a fair hearing challenging VESID's denial to provide college sponsorship. Ms. Armstrong has a psychiatric disorder and had been enrolled in a graduate rehabilitation counseling program at Syracuse University since 1985. Ms. Armstrong had 19 remaining credits to complete the program requirements when VESID proposed to discontinue sponsorship due to the length of time it had taken to complete the program to date. CAP argued for individualized services as required under the Rehabilitation Act of 1973 and documented the medical and extenuating circumstances in Ms. Armstrong's case which necessitated an extension of the typical time limits on college sponsorship.

The decision reached by the hearing officer noted "it was not good rehabilitation practice" for Ms. Armstrong not to have been advised in advance of the limitations on college sponsorship and recommended that VESID resume sponsorship.

VESID FAIR HEARING/ OCCUPATIONAL GOAL

The Upper-Hudson CAP Outreach Unit, Capital District Center for Independent Living, favorably represented a VESID consumer who experiences severe lower back pain and had been denied VESID sponsorship to pursue a career as a licensed practical nurse. Ms. Brown had previous training in the field of cosmetology and, because of her deteriorating back condition, could no longer perform in that field. VESID's objections to sponsorship centered on Ms. Brown's previous training and on the lack of employment prospects for an LPN with lower back problems. At the fair hearing, CAP documented the impact of Ms. Brown's limitations on her ability to perform in the field of cosmetology. CAP also produced comprehensive documentation which attested to employment prospects for an LPN in an array of occupational settings which do not require lifting. The hearing officer concurred on both points and directed VESID to sponsor Ms. Brown for LPN training.

VESID FAIR HEARING/ HOME MODIFICATIONS

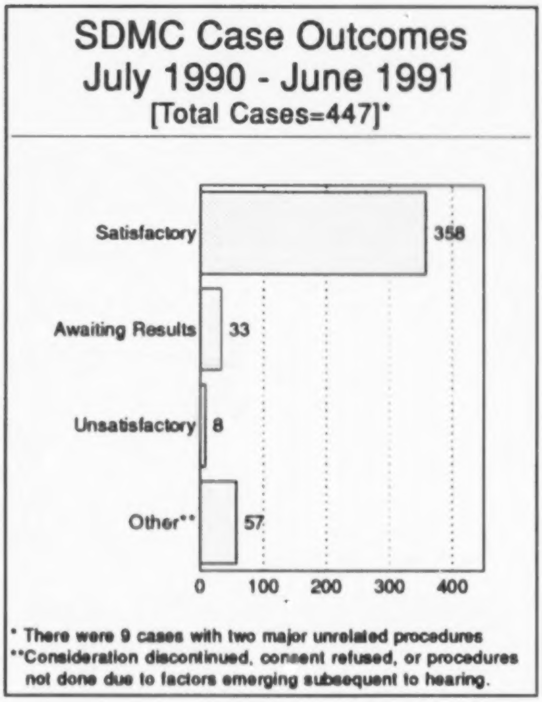
The Western New York CAP Legal Unit, Neighborhood Legal Services, assisted a VESID consumer with substantive problems associated with home modifications. Ms. Burke is a VESID consumer with muscular dystrophy who was in need of modifications to her bathroom. CAP was contacted after the contractor performing the modifications failed to meet several deadlines set by VESID for completion of the job. CAP determined that VESID had awarded the bid to a contractor who had no insurance and had failed to meet a number of accessibility standards in connection with the modification. As a result of the problems associated with the home modification, Ms. Burke was without a working toilet for two weeks and had no working sink or shower for approximately five months. With CAP's intervention, the contractor was dismissed from the job and the head of the architectural firm who had been engaged to assess the modification requirements agreed to act as the job supervisor. Due to the incompetence of the initial contractor, Ms. Burke's home and its contents were covered with dirt and grit from the use of jack hammers to tear out the bathroom floor without appropriate precautions. The local VESID office indicated that they could not pay for costs associated with the extensive cleanup required to bring Ms. Burke's home back to its original condition. CAP requested a waiver from VESID Central Office to reimburse the cleaning firm hired by the consumer. After nearly a one month delay, with the cooperation of the VESID service review unit, VESID agreed to reimburse the cleaning firm and the consumer for expenses incurred to date.

VESID FAIR HEARING/DRIVER TRAINING

The Long Island CAP Outreach Unit, Long Island Advocacy Center, represented a 54-year-old VESID consumer at a fair hearing with challenging a VESID denial to provide driver training. Mr. Woodward has limitations resulting from a stroke and had called CAP on short notice for representation at a scheduled fair hearing. VESID had determined that Mr. Woodward was not a suitable candidate for driving due to his various limitations. Upon review of the record, CAP cited a driver training evaluation which indicated that Mr. Woodward had moderate cognitive and perceptual problems, which would suggest that driving was not appropriate; however the report also indicated that therapy could potentially eliminate the limitations relative to driving. CAP recommended that VESID provide a service plan of appropriate therapy, and the hearing officer concurred. Mr. Woodward is currently engaged in a therapy program.

THE SURROGATE DECISION-MAKING COMMITTEE PROGRAM

The Surrogate Decision-Making Committee Program (SDMC) administered by the Commission has proven to be an effective alternative to the judicial system for providing timely consents to major medical treatment on behalf of residents living in mental hygiene programs who lack the capacity to make such consent, and without relatives or guardians to provide consent. The SDMC program currently operates in a 14-county area.


SDMC Case Outcomes
July 1990 - June 1991
[Total Cases=447]*

* There were 9 cases with two major unrelated procedures
**Consideration discontinued, consent refused, or procedures not done due to factors emerging subsequent to hearing.

At the heart of the SDMC program are the dedicated volunteers who compose the panels. The SDMC committees operate through four-person panels composed of a health care professional, a lawyer, a former patient or relative or an advocate, and a person with expertise or interest in the care of persons with mental disabilities. These doctors, nurses, lawyers, family members, and advocates donate considerable time to review the SDMC cases in a professional, efficient, and caring manner.

The panels receive and review the proposed major medical treatments when no family member or guardian is authorized or willing to make the decision for a patient. If the patient/resident is deemed to lack the capacity of making his/her own decision, the panel is authorized to provide substitute consent, or refuse the proposed treatment. The panels always meet with the patient before making any decision, and in providing or refusing consent for medical treatment, consider the relative risks and benefits, alternate treatments, quality of life with or without the treatment, and the previously expressed values and beliefs of the patient/resident.

Since its beginning in April 1986, the SDMC program has assisted 2,047 individuals in decisions related to major medical treatment. During the reporting period, the program reviewed 447 cases in which 392 individuals were given consents to receive major medical treatment which had positive effects.

EDUCATION AND OUTREACH

Education and outreach efforts provide further opportunities to monitor and advocate for quality services for people with disabilities. The Commission continues to place great value and resources on reaching and educating people with disabilities, their parents, advocates, and service providers. The following are representative activities from the reporting period:

PADD TRAINING ACTIVITIES

The Protection and Advocacy network continues to provide educational and training activities and provide outreach in a variety of settings, for example:

- ☐ The PADD Program at Albany Law School, in addition to offering specific courses on the law related to persons with disabilities, utilizes law students as part of the Disabilities Law Clinic to assist in the representation of cases.

☐ The New York City PADD Program sponsors a Physicians Grand Rounds Training Program in cooperation with the parents group, Parents and Advocates for Children's Services. This forum addresses the need for sensitivity to parents when they learn that their child has a disability.

☐ Each of the PADD programs has joined in an outreach and training program regarding the changes in eligibility for childhood Supplemental Security Income (SSI) brought about through the *Zebley v. Sullivan* class action lawsuit. The offices are attempting to reach former clients as well as heighten the awareness of other professionals who are in contact with children in need of services.

☐ Broome Legal Services Corporation PADD Program has stationed a full-time paralegal in their more rural Chenango County office as a part of a rural outreach program. The paralegal is a resident of the community and comes with a wealth of experience which has become valued by the area residents.

☐ Through letters to the editor in the *New York Times* and guest appearances on radio talk shows, the New York Lawyers for the Public Interest attempts to advise the community of the rights of individuals with developmental disabilities.

☐ Throughout the state, PADD educational advocacy training, concentrating on a special effort to reach parents of special education preschoolers, attempts to provide these parents with the skills necessary for another fifteen to seventeen years of involvement with the special education delivery system.

Disabilities Awareness

Conducted out of the Protection and Advocacy program, this project provides a "Speaker's Bureau" of volunteer staff within the Commission who visit elementary and middle schools to present information on the myths and realities of having a disability. Utilizing a disability awareness quiz as a focus for conversation, the presenters attempt to pave the way for better acceptance of students with disabilities. Student participants in the program are then encouraged to depict what they have learned either in essay or art form in a statewide competition. The winners of the past year's competition were treated to a trip to the state capitol in Albany where they received their awards from the state's first lady, Mrs. Matilda Cuomo, at the Governor's Mansion.

Minority Outreach

The Commission's New York City PADD office continues its minority outreach program to assist minority individuals (Blacks, Hispanics, Asian/Pacific Islanders and Native Americans) with disabilities and their families in accessing services from the Commission and its extensive network of advocacy organizations. Although situated in the New York City PADD outreach office, this program has a statewide focus. The New York State population shift indicates a decline in the white non-Hispanic and a marked upswing in the minority population. Loretta Goff, the coordinator of this program, has been cited for her untiring efforts with "Beyond Barriers, A Minority Perspective on Service Delivery," a statewide program in minority outreach. The program, during the past year, has developed a special poster which has been successful in producing many inquiries and requests for assistance from minority individuals and their families.

Training on Investigation of Deaths

The Commission's Mental Hygiene Medical Review Investigations Bureau provided training to staff members from other states on how it proceeds with investigating deaths of patients in the mental hygiene system. This three-day training held at the Commission's Albany office was attended by staff from Michigan, Vermont, New Jersey, and Connecticut, as well as New York. Included in the training were reviews of specific death types (such as restraint, suicide, choking, and medical neglect) as well as an overview of the Commission and its mandate to review all deaths in the mental hygiene system. Participants rated this training as excellent and stated that the information provided would be helpful to them in their own states.

Disability and the Law

This is the fourth year of a collaborative public outreach effort among the Commission, the New York Bar Association's Committee on Mental and Physical Disability, and the New York State Commission on Cable Television. Targeted for 800 cable TV stations, each of the programs produced is an hour in length and concentrates on legal issues encountered by persons with disabilities. This year the series concentrated on "Sexuality Issues for Persons with Disabilities" and is in the production stage for a professionally acted and scripted vignette on living with deafness in New York City. A two part series on the developmentally disabled offender is also in the planning stages. At the end of each show, the viewer is provided with the Bar Association's toll-free Lawyer Referral Information Service telephone number and the Commission's toll-free number for accessing the Protection and Advocacy program.

PAMII PUBLIC FORUMS

The PAMII program held public meetings in New York City and Syracuse to provide opportunities for interested and knowledgeable individuals to give comments on the PAMII program's activities and priorities. These meetings were held in accessible public places and were scheduled both during daytime and evening hours to accommodate work schedules for people who wished to attend. In addition to the public forums, notices invited letters and phone calls for comment, which prompted numerous responses from constituents using these opportunities. Among the major areas and issues discussed from these contexts were: investigation of allegations of abuse/complaints, smoking in psychiatric hospitals/units, underserved/unserved populations, residences for mentally ill individuals, and rights issues.

OTHER ACTIVITIES

Commission staff continue to provide inservice sessions to people in New York State and other states on issues related to quality of care, patient abuse, sexuality, informed consent, facility reviews, advocacy, etc. The Commission newsletter remains a special vehicle for regular communication of Commission activities and concerns to a statewide and national audience.

LOOKING AHEAD

CHILDREN'S SERVICES REVIEW

Over the past three years, the investigation of child abuse and neglect reports, pursuant to the agency's responsibilities in the Child Abuse and Prevention Act of 1985, has brought the Commission often to the doors of long-term residential care programs operated or licensed by the Office of Mental Health. Unfortunately these focused visits, while providing some insights, have not allowed a thorough study of the programmatic and cost-effectiveness of these programs. In particular, they have not helped the Commission to gain a broad perspective of the capability of these programs to meet individual children's needs.

In a systematic study, the Commission plans to look more carefully at the characteristics of the children served, as well as the services, outcomes, staffing, and costs of long-term residential programs for children with serious emotional problems in the state. The study will examine traditional congregate care settings including state-operated inpatient children's psychiatric centers and units and licensed residential treatment facilities, as well as the Office of Mental Health's newer community-based models, like community residences for children and family-based treatment, an enhanced foster care home model especially designed for children with emotional problems.

In total, the Commission plans to visit 18 different residential programs and to examine the services received by 100 children and adolescents in care. The study will also follow a smaller cohort of 30 children leaving one of these long-term residential models to determine how well they have adjusted in the 18 months subsequent to their discharge.

CHILDREN'S UNITS REVIEWS

Also flowing from implementation of the Child Abuse and Prevention Act of 1985, Commission staff have spent time investigating allegations of child abuse in hospitals providing acute psychiatric care for children. Although less than 10 percent of the reports of alleged child abuse involving mentally ill children received by the Commission originate from hospitals providing acute psychiatric care, these facilities serve a much larger number of children over shorter periods of time.

The Commission plans to become more familiar with children receiving acute care and issues involved in their care.

CHILDREN'S MEDICATION STUDY

A review of psychotropic medication practices in the spring of 1990 in eight OMH operated facilities serving children revealed strikingly high compliance with many of the OMH prescribing guidelines. Both in the current drug regimens of the youngsters and in their prior ones, physicians' prescribing practices ensured patient safety through careful consideration of dosage titration, avoidance of polypharmacy and attention to the intended and side-effects of the medications.

In contrast, in half the cases, there was no evidence that informed consent had been obtained from a parent or guardian, and in many of the remaining cases, there was inadequate information about how consent had been obtained and what information had been provided to the person providing the consent. Compounding these weaknesses was the virtual absence of drug-free periods, which are intended to ascertain the continuous need for medications, and the lack of effective individualized behavior management plans for over half the children in the sample. Finally, the Commission found a heavy use of PRN and STAT medication orders to deal with behavioral problems in the absence of individualized behavior plans or other less intrusive strategies.

This last finding raises several questions central to the welfare of children in inpatient psychiatric settings: Is there an over-reliance on medications to control youngsters? What does this reliance teach children about control of their own behaviors and what does it teach children about the purpose of drugs and the relationship between drugs and behavior.

A Commission report will be published in early 1992. In its response to the draft report, the OMH reported that the use of PRN/STAT medications would be reviewed by the Restraint and Seclusion Task Force, which is studying the broad question of how best to deal with out-of-control behavior.

DISCHARGE PRACTICES IN LICENSED PSYCHIATRIC UNITS OF GENERAL HOSPITALS

In response to a request from the NYS Office of Mental Health (OMH) and the State Hospital Review and Planning Council (SHRPC), the Commission has agreed to conduct a study of discharge practices and outcomes for patients leaving psychiatric units of general hospitals in New York State. Both parties are interested in knowing whether hospital practices and outcomes for patients had changed significantly since 1988 when the Commission's first study was conducted.

This study (*Discharge Practices of Inpatient Psychiatric Facilities*, August 1988) traced the experiences and outcomes of 60 individuals and concluded that nearly 40% of these men and women had lost all known contact with mental health providers within six months of their discharge, and that many of the individuals had encountered serious problems in the relatively short time since they had left the hospital. The study also found that most patients discharged from psychiatric units of general hospitals were not afforded comprehensive discharge plans and that many left the hospital with no specific appointment for mental health outpatient care.

Since the issuance of this initial report, the Office of Mental Health has attempted to initiate a number of reforms in outpatient services and the certification and reimbursement of inpatient and outpatient providers to correct problems noted in the Commission's study. Of particular importance, the Office has changed the rate reimbursement for both outpatient and inpatient psychiatric services to encourage service provision to persons with serious and persistent mental illness and to reward hospitals for discharge planning, and outpatient providers for serving former inpatients within the first month of their discharge.

In this second study, the Commission will follow a sample of 100 individuals discharged from ten hospitals in five different counties of the state. Unlike the first study, this study will also include direct input from the former patients and their family members. Additionally, the study will focus more substantively on understanding the barriers to effective discharge planning from the perspective of the hospital staff and the difficulties of inpatient and outpatient providers in coordinating service delivery for persons with serious and persistent mental illness.

The Commission hopes to issue a preliminary report of its findings to the Office of Mental Health, the State Hospital Planning and Review Council, the Governor and the State Legislature in the Spring of 1992.

REVIEW OF FAMILIAL ABUSE ALLEGATIONS OF ADULTS WITH DEVELOPMENTAL DISABILITIES

Only a small percentage of the reports of alleged abuse and neglect received by the Commission describe allegations of abuse or neglect by a member of the family or household where the victim resides. These allegations represent only 5% of the total reports received, but they comprise 10% of the reports filed by mental retardation programs and nearly 25% of the reports filed by day programs serving persons with developmental disabilities.

In reviewing these familial abuse and neglect reports, the Commission found that many providers cited these allegations as the most troubling reports they handle. They stated that these allegations are often more serious in terms of the actual harm or risk of harm to the alleged victim and are often the most difficult to investigate and resolve. Providers also reported, in a number of cases, that the alleged abuse or neglect had been recurring.

Based on the concerns of treatment providers and its own experience that allegations of familial abuse and neglect involving adults with developmental disabilities are often not well-handled by community agencies, the Commission concluded that a systemic study of a sample of these cases was warranted.

Study on Developmentally Disabled Parents

The Commission has been conducting a study on Developmentally Disabled Parents, in response to a request by the NYS Developmental Disabilities Panning Council. The evaluation will assess eight projects funded by the NYS Developmental Disabilities Planning Council, which have as a common focus the use of volunteers in working with parents with developmental disabilities to enhance their parenting skills and functioning. The projects differ substantially in terms of both their stated objectives and their self-evaluation criteria. According to the DDPC, the primary purpose of these projects is "to promote services to parents with developmental disabilities which will enhance family functioning." The eight projects are located across the state and, most of them reflect subcomponents of larger family support programs of their sponsoring agencies.

In view of both the variability among the projects, as well as the small size of most of the projects, an informal evaluation design was developed to focus on on-site observations and interviews with the project managers, the volunteers, and the parents with developmental disabilities and their children. In addition, a special subcomponent of the evaluation will provide a demographic, socio-economic, and functional profile of the parents served by the projects.

The Commission will provide the Developmental Disabilities Planning Council with a written evaluation report which addresses the objectives and evaluation questions that have been developed. Additionally, a mini-report profiling the parents with developmental disabilities served by the eight projects will be provided to the Council.

Adult Home Death Reviews

Since 1989, when the Commission was requested by the Legislature to review conditions in adult homes serving persons with mental illness, the Commission has made a concerted effort to identify and investigate unusual or unnatural deaths of mental health outpatients residing in adult homes. Individual case investigations into these deaths have resulted in pictures of men and women largely forgotten. Medication and medical needs in certain cases were neglected; changes in mental status in other cases were not reported to or followed up by appropriate service providers; complaints expressed at times by residents about conditions in homes or abuses were not acted upon.

The Commission has reported its findings of the individual case investigations to the Department of Social Services and the involved mental health service providers and adult home operators on a case-by-case basis. During the coming year, the Commission will also conduct a focused review of all residents of adult homes whose deaths are reported to the commission during a two-to-three month period.

Restraint Study

The 1992-93 State Appropriations Budget contains a directive from the New York State Legislature that "the Commission shall conduct a study of restraint and seclusion policies and practices of mental hygiene facilities or programs, for the purpose of identifying procedures that will promote the protection of the life and safety of patients including but not limited to an assessment of procedures that minimize the use of restraint and seclusion and ensure effective staff training, and make recommendations thereon to the governor and legislature."

1990-91 PUBLICATIONS

In the Matter of Joseph Conway
December 1990

Inmates with Developmental Disabilities in New York State Correctional Facilities
March 1991

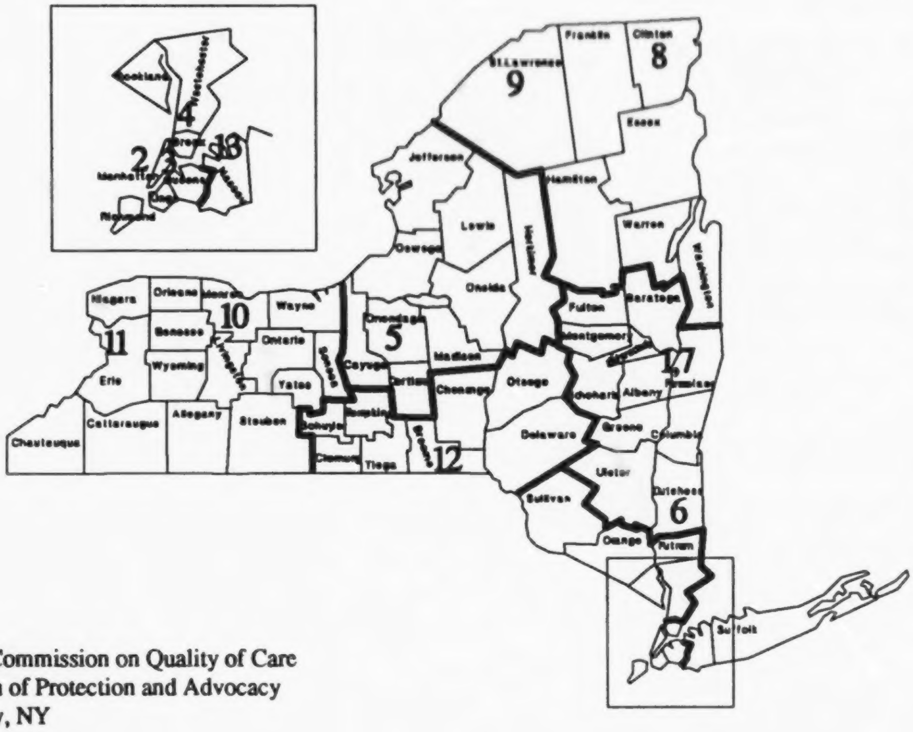
In the Matter of Michael Goldstein:
An Emergency Room Patient Discharged by Genesee Hospital
June 1991

In the Matter of Timothy Smythe:
A Patient at Central New York Psychiatric Center
August 1991

In the Matter of the Jacob Home:
An Uncertified Adult Home Serving Residents with Mental Illness
August 1991

Child Abuse and Neglect in New York State Office of Mental Retardation and Developmental Disabilities Residential Programs
February 1992

PROTECTION AND ADVOCACY FOR DEVELOPMENTALLY DISABLED PERSONS REGIONS AND OFFICES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1. NYS Commission on Quality of Care
   Bureau of Protection and Advocacy
   Albany, NY

NEW YORK CITY REGION

2. NYS Commission on Quality of Care
   Bureau of Protection and Advocacy
   New York, NY
3. New York Lawyers for the Public Interest, Inc.
   New York, NY

LOWER HUDSON REGION

4. Westchester Independent Living Center, Inc.
   White Plains, NY

CENTRAL REGION

5. Legal Services of Central New York, Inc.
   Syracuse, NY

UPPER HUDSON REGION

6. Mid-Hudson Legal Services, Inc.
   Poughkeepsie, NY
7. Disabilities Law Clinic at Albany Law School
   Albany, NY

NORTH COUNTRY REGION

8. North Country Legal Services, Inc.
   Plattsburgh, NY
9. North Country Legal Services, Inc.
   Canton, NY

WESTERN REGION

10. Western New York Advocacy for the
    Developmentally Disabled, Inc.
    Rochester, NY
11. Neighborhood Legal Services, Inc.
    Buffalo, NY

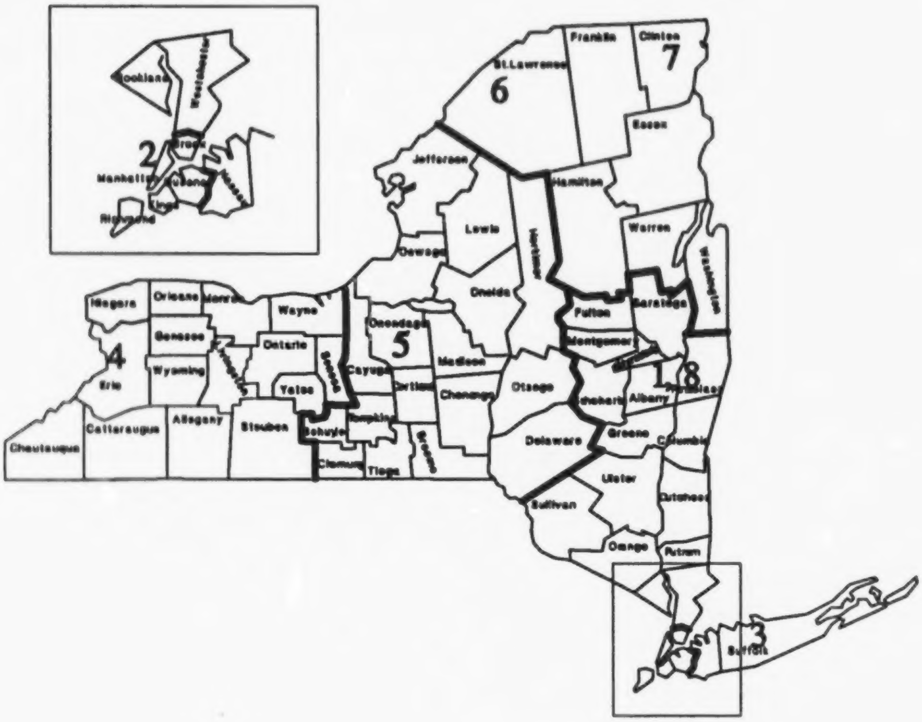
SOUTHERN TIER REGION

12. Broome Legal Assistance Corporation
    Binghamton, NY

LONG ISLAND REGION

13. Long Island Advocates, Inc.
    New Hyde Park, Inc.

PROTECTION AND ADVOCACY FOR MENTALLY ILL INDIVIDUALS REGIONS AND OFFICES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1. NYS Commission on Quality of Care
   Bureau of Protection and Advocacy
   Albany, NY

NEW YORK CITY REGION

2. New York Lawyers for the Public Interest, Inc.
   New York, NY

LONG ISLAND REGION

3. Touro College
   Jacob J. Fuchsberg Law Center
   Huntington, NY

WESTERN NEW YORK REGION

4. Neighborhood Legal Services, Inc.
   Syracuse, NY

CENTRAL NEW YORK REGION

5. Legal Services of Central New York, Inc.
   Syracuse, NY

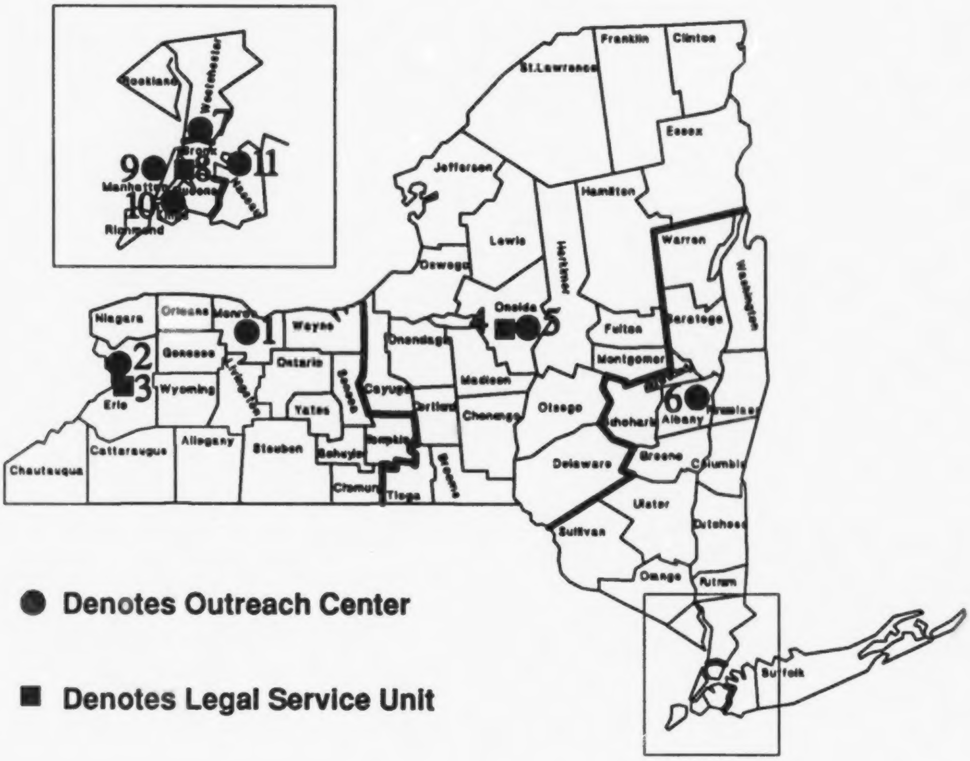
NORTH COUNTRY REGION

6. North Country Legal Services, Inc.
   Canton, NY
7. North Country Legal Services, Inc.
   Plattsburg, NY

HUDSON VALLEY REGION

8. Disability Advocates, Inc.
   Albany, NY

CLIENT ASSISTANCE PROGRAM REGIONS AND OFFICES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● **Denotes Outreach Center**

■ **Denotes Legal Service Unit**

WESTERN NEW YORK REGION

1. Rochester Center for Independent Living, Inc.
   Rochester, NY
2. Rochester Center for Independent Living, Inc.
   Buffalo, NY
3. Neighborhood Legal Services, Inc.
   Buffalo, NY

CENTRAL NEW YORK REGION

4. Resource Center for Independent Living, Inc.
   Utica, NY
5. Legal Aid Society of Mid-York, Inc.

HUDSON VALLEY REGION

6. Capital District Center for Independence, Inc.
   Albany, NY
7. Westchester Independent Living Center, Inc.
   White Plains, NY

NEW YORK CITY REGION

8. New York Lawyers for the Public Interest, Inc.
   New York, NY
9. Center for Independence
   of the Disabled in New York, Inc.
   New York, NY
10. Brooklyn Center for Independence
    of the Disabled, Inc.
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LONG ISLAND REGION

11. Long Island Advocacy Center, Inc.
    New Hyde Park, NY

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Jane Greengold Stevens
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Seymour Barasch
Chrarles King
Robert C. Mayo, D.D.S.
Polly Panzella
Florence Portnoy
Harry Portnoy
Thomas J. Prisco
Margaret Raustiala
Jerome Rosenblit
Mary Taylor

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Richard M. Cohen, Ph.D.
Martin B. Duke, M.D.
Sister Margaret Flood
Evelyn Gulliksen, R.N.
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Adele Landesberg, R.N.
Risa A. Leonard, R.N.
Morrison S. Levbarg, M.D.
Kathleen Ryan
Monsignor John T. Servodidio
Albert B. Siewers, M.D.

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R. Adam Forno
David Freschi
Claire Harnick
Helen R. Hines
Fr. Gerald D. Kampfer
Jan Larsen
Ronald S. Lehrer
Douglas P. Mackechnie
Marie Meehan
P. Aaron Moskowitz
W. Bruce Newman
Marion Ostrander
Bonnie M. Page
Eleanor C. Pattison
Michael Payeur
Lucille Pritchard
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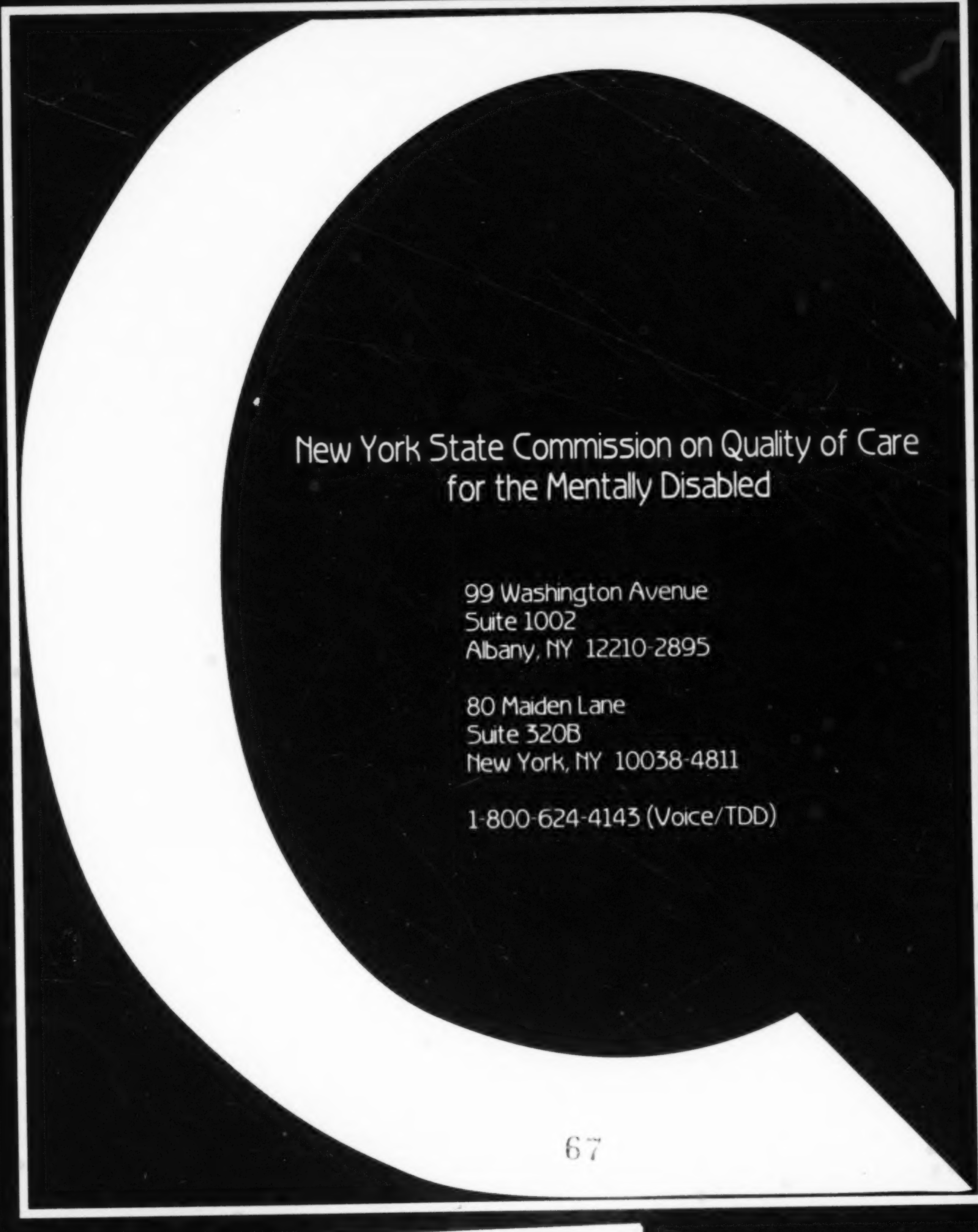

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